

NORTH DAKOTA'S TITLE V FIVE-YEAR NEEDS ASSESSMENT

A. Needs Assessment Process

Title V legislation requires that State's prepare a statewide needs assessment every five (5) years that identifies the need for:

- Preventive and primary care services for pregnant women, mothers and infants;
- Preventive and primary care services for children; and
- Services for children with special health care needs.

North Dakota (ND) has completed this requirement using the suggested conceptual framework outlined in the Title V Block Grant Guidance.

B. Five Year Needs Assessment

1. Process for Conducting Needs Assessment

State's Overall Needs Assessment Methodology

Late in 2003, the ND Title V program began planning the five-year needs assessment of the maternal and child health population for the FY 2006 Title V Maternal and Child Health (MCH) Block Grant Application. A work group was established with leadership from the State Systems Development Initiative (SSDI) Coordinator. The work group consisted of representation from the state CSHCN program and five of the six divisions in the DoH's Community Health Section (Family Health, Nutrition and Physical Activity, Injury Prevention and Control, Tobacco Prevention and Control, and Chronic Disease). Throughout the process, informal collaboration occurred with the Primary Care Association, the Primary Care Office and family organizations such as Family Voices and the CSHS Family Advisory Council.

The first task of the workgroup was to identify a list of data sources and indicators. The data sources were divided into two groups: primary sources and secondary sources. The indicators were categorized as 1) population and demographic, 2) pregnant women, mothers and infants, 3) children and adolescents, 4) children with special health care needs, and 5) health system capacity indicators. The indicators for the three MCH population groups were further grouped as health status, health care access or utilization, or health risk indicators. Because of small populations in ND and small numbers of annual health events, many indicators were grouped into three or five-year averages to achieve stable rates. Trends were assessed over the five-year period since the last assessment to the current assessment, either from 1997-2001 or 1998-2002.

The workgroup then identified a list of key stakeholders and conducted a Stakeholder Survey. This survey/assessment involved both the collection of data and expert opinion from MCH partners as to their perceptions of health problems. Health issues were identified for each of the three MCH population groups (women, mothers and infants; children and adolescents; and children with special health care needs) as well as the entire MCH population. Survey respondents were asked to select the top five health issues in each of the four categories. Space

was left in each of the categories so respondents could identify a health need that may not have been listed. Results from the stakeholder survey were used to identify data resources relevant to the identified top five health issues in each of the three population groups. The workgroup then formed into three subcommittees that represented the MCH population groups.

October 28, 2004 was the date selected for the MCH and CSHS Planning Retreat. More than forty individuals representing Title V staff, state and community partners, and stakeholders attended the retreat. The retreat facilitator led participants through a need prioritization process organized within the three MCH population groups. Each group identified priority needs, but were unable to rank them according to importance. Each group then wrote specific need statements for each of the priority needs.

After the retreat, three small workgroups were formed for each of the three population groups. Workgroup members consisted of Title V staff with programmatic expertise about specific needs as well as outside stakeholders. Workgroup members worked through a process designed to sort the priority needs for their population group into one of three lists based on pre-determined criteria. Based on this criteria, ten priority needs were selected which were chosen for the ten state “negotiated” performance measures for the next five-year grant cycle.

After the selection of the state's 10 priority needs and development of state-negotiated performance measures, individual staff persons from the MCH program were assigned primary responsibility for each national and state performance measure that closely related to their programmatic area of expertise. CSHS program staff opted to work on CSHCN related performance measures as a group. The SSDI coordinator, who works with both Title V programs, was responsible for the collection and reporting of data for each measure and for monitoring the overall process.

For each assigned performance measure, staff were directed to write an annual plan and a process to monitor the successful completion of the activities that was designed to impact the performance measure. Staff were also required to write an annual report for their assigned performance measure in which they commented on achievement of the objectives and summarized progress on the work plan activities. Staff were provided trend data for their measure(s) from which they provided five-year target projections. Title V resources are directed towards these ten priority areas.

The ND Title V program conducts and sustains an ongoing needs assessment of the MCH population through continued collection and analysis of primary and secondary data. Health status and health system capacity indicators are collected annually and reported in the MCH Block Grant. Title V staff participate in a Healthy People 2010 workgroup in which data for most of the objectives are collected annually. When available, data is stratified by race, age and socio-economic status.

The state Title V program obtains resident birth certificates, along with infant and child death certificates and fetal death certificate files annually from the Division of Vital Records. The birth certificate file and the newborn screening file and infant death file are linked to the birth

file annually. These data are used to track birth outcomes, risk factors and mortality for the state's MCH population.

The state Title V program participates in several ongoing surveillance activities. The Behavioral Risk Factor Surveillance System (BRFSS) is conducted annually and results for the subgroup of females age 18-44 is extracted to assess ongoing behavior and health risks for women of childbearing age. The ND Department of Health (DoH) collaborates with the state Department of Public Instruction to conduct a high school and middle school Youth Risk Behavior Survey (YRBS) every two years. A workgroup publishes and disseminates a summary of the survey results. ND conducted a Point-In-Time Pregnancy Risk Assessment Monitoring System (PRAMS) survey in 2003. Results are being used to assess the health status of women who have had a recent birth.

The state Title V program developed the ND Birth Defects Monitoring System in 2003. This passive tracking system collects secondary data from Vital Records, health care claims, and Children's Special Health Services (CSHS) specialist and clinic reports on selected birth defects affecting ND resident children. Forty-five separate birth defects including congenital heart defects, neural tube defects, and cleft lip and palate are included in the system, along with several major chromosomal anomalies. A summary report of findings was published and distributed in early 2004.

The state Children with Special Health Care Needs (CSHCN) program collects ongoing data on approximately 1,400 children served directly through CSHS annually. In addition to demographic and diagnostic information, data is collected on insurance status, clinic and specialty visits.

Formal and Informal Collaboration Processes and Partnerships

ND has many strong collaborative partnerships with the public and private sector, along with State and local levels of government.

MCH and CSHS staff works with other state agency staff on a daily basis through numerous coalitions, taskforces, advisory groups, committees and cooperative agreements. State CSHCN staff currently participates in 39 interagency committees, thus assuring collaboration on a wide range of issues of importance to CSHCN's and their families. CSHS supports a nine member Family Advisory Council to assure family involvement in policy, program development, professional education, and delivery of care. A Family Advisory Council member was an active participant in the Title V Retreat. In addition, information regarding the selected priority needs were brought back to the full Council for additional feedback. Other groups that received information regarding the needs assessment priorities included the ND Chapter of the American Academy of Pediatrics, the Interagency Coordinating Council and the CSHS Medical Advisory Council.

MCH staff work closely with the state local health liaison, whom acts as the link between the ND DoH and local public health units and other key public and private partners. In addition, the public health liaison assists in the facilitation of the quarterly local public health administrators'

and director of nursing meetings. MCH program staff attends these quarterly meetings to solicit program input and to provide program updates. The Title V Director attends all of the administrator and director of nursing meetings and provided regular updates on the five-year needs assessment process. The chair of the local public health administrators was an active participant in the Title V Retreat.

The Community Health Section (CHS) Advisory Committee reviews assessments of the health status of the MCH population and advises CHS on health issues related to the state's population. The Title V Director is an active participant of this Committee and presented the priority needs for review and comment. Feedback received from this Committee was used in the review process by the internal state workgroup.

Healthy North Dakota (HND) is a statewide initiative whose goal is to improve the health of every North Dakotan by inspiring people to establish personal behaviors and support policies that improve health and reduce the burden of health-care costs. *HND* works through innovative statewide partnerships to support North Dakotans in their efforts to make healthy choices – in schools, workplaces, senior centers, homes and anywhere people live, work and play. Many of *HND* priority areas and committees are directly related to the ten priority needs identified through the five-year needs assessment process. The *HND* Director was an active participant in the Title V Retreat. In addition, many MCH program staff are active members of *HND* workgroups.

Quantitative and Qualitative Methods

Both quantitative and qualitative methods were used effectively in the needs assessment process.

One of the criteria established for the inclusion of indicators, was to have a reliable, ongoing data source with consistent collection methodology and the ability to stratify the data in order to compare the indicator to another population group. When possible, state data were compared to national data for the same indicator to assess differences in health status. To assess disparity among different population groups, state data were stratified in three ways: by race, socio-economic status and geography. When possible, data for White residents were compared to the American Indian population in the state. A comparison of the Medicaid population and the non-Medicaid population was used as a proxy for socio-economic status. Geographic disparity was assessed by looking at eastern and western areas of the state and urban and rural/frontier areas. Stratification was done based on zip code and county of residence and designation of the three Metropolitan Statistical Areas (MSAs) in the state.

Qualitative methods used included:

- Stakeholder Survey (Assessment included both the collection of data and expert opinion as to the perceptions of health problems.)
- Stakeholder input in breakout priority identification workgroups during the Retreat.
- Children's Service Coordinating Committee (CSCC) retreats regarding early childhood
- CSHCN Family Focus Groups, Pediatric Survey, and CSHS Family Survey

Methods Used to Assess the State's Capacity

The state's capacity to provide direct services was assessed by identifying provider distribution in the state. ND counties designated as Health Professional Shortage Areas and Dental Health Professional Shortage Areas along with Medically Underserved Areas were identified. In addition, the number of health care facilities and beds along with practicing specialty care and related service providers were collected. Health care facilities included Rural Health Clinics, Critical Access Hospitals and Acute Care Hospitals. Medical specialists assessed included dentists, family practice physicians, OB/GYNs, psychiatrists, pediatricians and other pediatric specialists. Related service providers included nurses, physical therapists, occupational therapists, respiratory therapists, speech/language pathologists and audiologists.

ND has three Metropolitan Statistical Areas (MSAs). The location of primary practice for each of the facilities, medical specialists and related service providers was identified and was compared to the location of the state's MCH population. It was found that the vast majority of the direct care providers practice in one of the three MSAs while only about half of the MCH population resides in one of the MSAs, resulting in geographic access issues.

All Sources Used

Secondary Data Sources:

Secondary data sources used for the needs assessment included birth, death, and fetal death certificates from Vital Records. Death certificate data was used to assess the number and causes of deaths to infants, children and women age 18-44 in the state. Birth certificate data, and linked birth and infant death files were used to assess birth outcomes and maternal risk factors. United States birth and death data was also collected from the National Vital Statistics System and compared to ND data to assess differences between state and national rates.

Health care claims information, which includes hospital discharge data, as well as ambulatory care data for the population covered by Medicaid and most private insurance carriers in the state, was also collected. It is estimated the system contains 70-75 percent of all health care activity in the state. The claims information was used to estimate prevalence of chronic disease and ambulatory sensitive conditions in the MCH population and to assess the major causes of inpatient hospitalization.

Data from the US Census Bureau and the ND State University (NDSU) State Data Center were used to determine the population of infants, children, and women of childbearing age in the state. Race, age and county of residence for the MCH population were collected from the 2000 Census. In addition, Census information provided data on income and poverty status. Population, family composition, economic condition, child care, education, and risk status indicators of children by county and region in ND is collected from Kids Count annually.

Program data were collected from a number of public health programs such as Women, Infants, and Children (WIC), Family Planning, and the Optimal Pregnancy Outcome Program (OPOP). Behavioral surveillance studies and statewide epidemiological surveys were used to collect

information on the oral health status of children in ND. Both the Pregnancy and Pediatric Nutrition Surveillance Systems were used to collect data of the nutritional and health status of low-income women and young children participating in the state WIC program.

The number of children and demographic characteristics of children served directly through the CSHS Unit in the ND Department of Human Services (DHS), the state's CSHCN program, was collected. Diagnostic and insurance status information was also collected from CSHS program data. The Mental Health and Substance Abuse and Disability Services Divisions in DHS and the Special Education program in the Department of Public Instruction provided additional data on children with special health care needs.

Child abuse and neglect reports and foster care data were obtained from the Children and Family Services Division in DHS. Data were collected from the Medical Services Division on enrollment in the state's Medicaid, Healthy Steps (SCHIP) and Health Tracks (EPSDT) programs.

Data on child restraint and seat belt use for infants and young children were collected from booster seat surveys, car seat checks and observational studies conducted by the state's Injury Prevention program. Crash facts from the state Department of Transportation were used to assess the degree of injuries resulting from motor vehicle crashes in the MCH population. The Bureau of Criminal Investigation in the State Attorney General's office and domestic violence agencies throughout the state provided data on domestic violence affecting women and children in the state.

Several provider organizations and professional organizations were contacted to assess the number of health care professionals and related services providers in the state and to determine the geographic location of their practice. The Center for Rural Health at UND School of Medicine, along with the ND Primary Care Office, provided data on the availability of health care providers and medically underserved and health professional shortage areas across the state. Geographic mapping was used for much of the county level data to assist in identifying geographic disparities for a number of the indicators.

Other secondary data sources used for the needs assessment included:

According to New American and Refugee Families: When Children Have Special Needs, a publication by the ND Center for Persons with Disabilities, more than 12,000, or two percent of the state's population in 2000, were foreign born. Approximately half are naturalized citizens and half are not citizens. Half of them entered the United States between 1990 and 2000. Six percent of North Dakotans indicate they primarily speak a language other than English. Most of the state's immigrant and refugee families live in the eastern part of the state, primarily in Cass, Walsh and Richland Counties. Most foreign-born people who are new Americans tend to live in urban areas, and have a larger household size and higher rates of unemployment than other citizens in the state. They also tend to have lower levels of education and income and are less likely to have health insurance.

According to North Dakota County Out-Migration Flows: 1998-99 to 2000-01, by the ND State Data Center at NDSU in 2002, more wage earners moved out of the state than moved in, resulting in a loss of income for the state. Net loss in taxable income for the state due to out-migration was nearly \$400 million, resulting in increasing loss of revenue for the state.

The seven Community Action agencies in the state conducted a ND Community Action Statewide Low-Income Needs Assessment in 1998 and in 2003. A questionnaire was completed by individuals receiving services from Community Action agencies in which fifteen needs were ranked. The second most prevalent need identified was dental care (44 percent) and the fifth highest need was general health care (38 percent). Of people needing child care, 16 percent said having a special need child was a barrier to receiving the service.

The ND Healthcare Association, the state's Primary Care Association, completed a Marketplace Analysis in 2001. Important findings included the impact of residents leaving the state to receive health care services, and the impact of the farm crisis on rural residents. The analysis recommended the following strategies: improvements in data collection and reporting, assessment of market areas, and expansion of participating primary care delivery sites. One priority identified was in keeping health care access available to all residents in all portions of the state.

ND received a Health Care Planning Grant to conduct a survey of health insurance coverage in the state in early 2004. The survey assessed underinsurance as well as insurance coverage status. At the time of the survey, 8.2 percent of North Dakotans were found to be uninsured. The rate differed significantly by race, with only 7 percent of the state's White population uninsured compared to 31 percent of American Indian residents. The uninsured tended to have lower income and education levels than people with insurance, but most were employed. Cost was the primary reason given by the uninsured for not buying insurance on their own.

Primary Data Sources:

Data was also collected from a number of ongoing surveillance systems in the state. Data were available from the CSHCN State and Local Area Integrated Telephone Survey (SLAITS) and a separate family survey conducted by the state CSHCN program. In addition, data on CSHCN were obtained from family focus groups and a pediatric provider survey. A needs assessment survey conducted by Family Voices of ND, Inc. assessed the capacity of the service system to address the needs of children with special health care needs and their families.

Several additional primary data sources were used. The BRFSS was used to assess health risk behaviors in females age 18-44. The ND Department of Public Instruction in collaboration with the DoH completes the YRBS biannually. YRBS is used to assess health risks and behaviors in high school and middle school students in the state. With support from CDC, ND conducted a Point-In-Time PRAMS survey in 2002. Survey results are helping to assess issues related to pre-pregnancy behaviors, access to prenatal care, the educational content of prenatal visits, access to health care, and education about infant care.

Strengths and Weaknesses

Data capacity and linkages have been strengthened through ongoing data collection and analysis, the availability of new data sources (e.g. PRAMS, Birth Defects Monitoring System), and the addition of qualitative data approaches (e.g. family focus groups). In addition, the Title V needs assessment process benefited from the involvement of many state level staff, community partners and family representatives.

ND has a declining population overall and among the MCH population. ND was the only state to lose population between the 1990 and 2000 Census. Low numbers of annual health events tend to create variability in rates from year to year. Without averaging, it is difficult to track trends and compare state rates to national rates for many health indicators.

Partly due to the lack of access to data, ND lacks the ability to adequately assess the capacity of the private and public health system to meet the needs of the MCH population. Although the state's population is becoming more urban and concentrated in four major population centers, much of rural ND has poor access to primary and specialty care providers. Although difficult to quantify, weather, geographic distances and socio-economic factors are also thought to influence access to care.

There are gaps in the ND health care claims system that make it difficult to draw accurate conclusions from the claims data. Private insurance claims are de-identified, so it is impossible to track a unique individual's health care history. In addition, the system does not include data on the uninsured and those whose primary source of care is Indian Health Service, two of the most vulnerable groups among the state's MCH population.

Future improvements may include:

- Incorporating local needs assessment and planning into the state level process.
- Improving integration of needs and capacity assessment by pyramid level.
- Better allocation of resources based on Title V identified priorities.

2. Needs Assessment Partnership Building and Collaboration

Methods Used to Build and Enhance Partnerships

Methods used to build and enhance partnerships are described throughout Section B. 1., Process for Conducting a Needs Assessment.

3. Assessment of the Needs of the Maternal and Child Health Population

Pregnant Women, Mothers and Infants

Demographic and Population Indicators

The birth rate in ND is declining. The state birth rate was 12.1 in 2002 compared to 13.9 for the United States overall. There were 7,976 resident births in ND in 2003. The state has not had more than 8,000 births in a year since 1997.

The number of women in the state age 20-44 decreased by 8,000 from 1990 to 2000. The number of White women decreased by more than 9,500 while the number of American Indian and women of other minorities age 20-44 increased by more than 1,500.

According to the 2000 Census, 15.3 percent of ND women age 18-44 were below the poverty line. However, there were extreme disparities by race. 13.3 percent of White women age 18-44 in ND were in poverty compared to 43.1 percent of American Indian women.

Health Status Indicators

Due to low number of annual events, the infant mortality rate in ND tends to fluctuate from year to year. The same is true for state fetal, neonatal and post-neonatal mortality rates. When infant mortality rates are averaged over three years, the state rate for 2000-2003 of 7.2 is slightly higher than the national rate of 7.0 in 2002. The leading cause of infant mortality in ND is congenital anomalies, followed by prematurity/short gestation and SIDS. Between 2000 and 2003, the percent of ND women of childbearing age taking a multivitamin or folic acid containing supplement has increased, but is still well below the Healthy People 2010 target. The percent of ND babies placed on their backs to sleep increased from 57 percent in 1996 to 77 percent in 2003.

During the five-year period 1999-2003, the American Indian infant mortality rate in ND was 10.5 compared to 6.6 for Whites. Between 1999 and 2003, the infant mortality rate for ND babies born to women whose birth was paid for by Medicaid was 8.0 compared to 6.7 for non-Medicaid.

During the 4-year period 1999-2002, there were 318 deaths to ND resident women age 20-44. Cancer (72) was the leading cause of death among these women followed by cardiovascular diseases (60), motor vehicle accidents (54) and suicide (24). The ND death rate per 100,000 for women 20-44 during this same time period was 72.4 compared to 95.3 for the US overall in 1999-2000. During this same five-year period, the death rate per 100,000 for ND American Indian women (214.9) was more than three times the rate for White women (65.1).

During 1999-2003, 6.3 percent of ND births were low birth weight (LBW). State LBW is consistently lower than the national percentage. American Indian babies actually had lower percent of LBW (5.6 percent) than White babies (6.6 percent). Babies on Medicaid (7.2 percent) had a slightly higher percent of low birth weight than non-Medicaid babies (6.1 percent). ND's

percentage of births born very low birth weight is consistently lower than the national percentage. During 1999-2003, one percent of babies born to American Indian mothers and 1.2 percent of White babies were born very low birth weight.

The ND Women, Infant and Children (WIC) nutrition program serves approximately 25,000 pregnant women, infants, young children under age five and their mothers each year. The prenatal and postpartum health status of women enrolled in WIC is monitored through the Pregnancy Nutrition Surveillance Systems (PNSS). This data helps to identify and reduce pregnancy-related health risks that contribute to adverse pregnancy outcomes. In addition to demographic information, data on several health indicators, prenatal behaviors, birth outcomes and feeding practices is collected at each WIC program site in the state.

ND data for each of these indicators in 2002 and historically is statistically similar to national data for all health indicators, with the exception of maternal tobacco use. ND WIC mothers were more likely to use tobacco three months prior to and during pregnancy – including the last three months of pregnancy – than women nationally. However, a higher percentage of ND women who quit smoking by their first prenatal visit stayed off cigarettes than women nationally.

Women in the ND WIC program who were under age 20 or had less than a high school education tended to have poorer health outcomes than women age 20 or older or with at least a high school education. American Indian women on average, tended to have poorer health outcomes than White women. American Indian women were more likely than White women to be overweight before pregnancy, use tobacco, and live in a household with smoking. They also were less likely to have had prenatal care beginning in the first trimester and breastfeed their baby.

The health of infants and young children enrolled in the ND WIC program is monitored through the Pediatric Nutrition Surveillance System (PedNSS). In addition to demographic information and the child's birth weight, the PedNSS monitors the child's height and weight, hemoglobin, and breastfeeding status during their first year of life.

Trends indicate an increasing percentage of young children being overweight, both in ND and nationally. American Indian children in the ND WIC program have substantially higher rates of obesity and overweight than White children. A decreasing number of ND WIC children are found to have low hemoglobin, a measure of anemia or iron deficiency – one of the most common nutritional problems among low-income populations. ND rates of anemia are lower than national rates reported in the PedNSS.

The percentage of ND mothers who breastfed their infant at hospital discharge increased from 57 percent in 1996 to 62 percent in 2002. During that period, 62 percent of White mothers breastfed, compared to only 41 percent of American Indian mothers.

According to the BRFSS, 11.4 percent of ND females age 18-44 report ever having been told by a health professional that they have asthma and 2.7 percent report having been told they have diabetes.

In a study of more than 16,000 women age 20-44 enrolled in the ND Medicaid program between 1999 and 2001, 4.1 percent had a health care claim in which diabetes was listed as a diagnosis and 7.9 percent had a claim indicating a diagnosis of asthma. Sixteen and one-half (16.5) percent had a claim indicating a diagnosis of depression and 14.3 percent with a diagnosis of anxiety. The table below shows the estimated prevalence of selected health conditions for women age 20-44 in the ND Medicaid program based on diagnostic information obtained from health care claims forms (Table 1).

Table 1: Mental Health Disorders

	Percent
Depression	16.5%
Anxiety	14.3%
Psychosis	13.0%
Substance Abuse	
Alcohol Dependence	6.3%
Drug Dependence	3.4%
Chronic Illness	
Asthma	7.9%
Diabetes	4.1%
Hypertension	5.1%

Diabetes rates were three times higher for American Indian women than White women. Asthma rates were higher among American Indian women (10.0 percent) than White women (7.3 percent). Asthma rates were also higher for women living in urban areas than rural areas. American Indian women with asthma tended to receive care in outpatient hospital or emergency department settings while White women were more likely to receive care for their asthma during office visits. Hypertension was more common among American Indian women and women living in rural areas.

The three most common conditions during pregnancy among ND women were pregnancy-associated hypertension, gestational diabetes and anemia. According to a study conducted by the DHS, for ND live resident births from 2000 through 2002, anemia was positively associated with mothers who were American Indian, lived in rural areas, had Medicaid as payer of their birth and were under age 20. Gestational diabetes was found to be associated with increased maternal age (>40) and lower maternal weight gain (< 20 pounds). Pregnancy-associated hypertension was found to be more common in women with a weight gain of more than 40 pounds during their pregnancy.

Health Care Access and Utilization Indicators

During the five-year period 1998-2002, 85 percent of ND mothers received prenatal care beginning in the first trimester, higher than the national percentage. American Indian women (68 percent) had lower rates of first trimester prenatal care than White women (88 percent). Women on Medicaid (75 percent) were lower than non-Medicaid recipients (88 percent).

The percentage of ND women receiving adequate prenatal care, as measured by the Kessner index, increased from 69 percent in 1998 to 73 percent in 2002. During the five-year period, American Indian women (50 percent) had lower rates of adequate prenatal care than White women (76 percent). According to the Kotelchuck index, women on Medicaid had lower rates of adequate prenatal care (71 percent) than non-Medicaid women (83 percent).

Among these women enrolled in Medicaid, there were 7,381 inpatient hospitalizations during the three-year period 1999-2001. Nearly two-thirds were admissions for newborn delivery and the majority of other hospitalizations were for acute and chronic illnesses (Table 2).

Table 2: Primary Cause of Hospitalization

	Number	Percent
Newborn Delivery	4773	64.7%
Vaginal (3711)		
Cesarean (1062)		
Acute and Chronic Illness	1693	22.9%
Other Reproductive Causes	742	10.1%
Mental Health and Substance Abuse	99	1.3%
Injury	74	1.0%

Over five and one half (5.7) percent of ND Medicaid women age 20-44 had a claim indicating a mammogram procedure had been done during the three-year period 1999-2001. Yearly mammograms are recommended for women over age 40. Of Medicaid women age 40-44, 22.7 percent had a mammogram. Of this group, White women and women living in urban areas were more likely to have had a mammogram than American Indian women or women in rural areas.

Of the more than 16,000 unduplicated women age 20-44 enrolled in Medicaid, just over half (54.5 percent) had a claim for a dental service or procedure during the three-year period. The percent was twice as high among White women (61.3 percent) than American Indian women (30.0 percent). The percent having a dental claim increased with age from 44 percent of women age 20-24 to 66 percent of women age 40-44. Claims for dental care were also higher among women living in urban areas, suggesting geographic access barriers.

In FY 2003, 1,913 women age 20-44 were enrolled in the state's Vocational Rehabilitation program. This comprises approximately one percent of the female population between 20 and 44. The leading diagnostic eligibility categories were mental illness, orthopedic impairments, alcohol and drug dependence, and learning disabilities.

According to the BRFSS, 88 percent of ND women age 18-44 reported having a source of health insurance in 2003. Nine percent reported costs as a barrier to receiving health care. Seventy-one (71) percent of women indicated they had a personal doctor or health care provider. In 2002, 38 percent of women age 18-44 reported ever having a mammogram, but 93 percent said they had at least one clinical breast exam.

Health Risk Factors

During 1998-2002, 28 percent of ND babies were born to unmarried mothers compared to 33 percent for the United States overall. In ND, the percentage of births out-of-wedlock was three times higher for American Indian women (69 percent) than White women (23 percent). Nearly two-thirds of mothers indicate their pregnancy was planned – saying they wanted to be pregnant at the time they got pregnant or sooner. Women on Medicaid during their pregnancy were less likely to have a planned pregnancy than women who were not on Medicaid.

More than three in five ND mothers breastfeed their infant at hospital discharge, but the percentage drops to one in five by six months among the WIC population. American Indian mothers breastfeed at a much lower rate than White mothers.

Between 1999 and 2003, 17.4 percent of ND mothers used tobacco during their pregnancy compared to 12 percent nationally in 2001. However, the state percentage decreased from a high of 20 percent in 1997 to 16 percent in 2003. During the five-year period 1999-2003, thirty-seven percent of American Indian mothers used tobacco during their pregnancy compared to only 15 percent of White women.

Between 1998 and 2002, approximately 79 percent of all resident ND births were vaginal and 21 percent cesarean. This is similar to the national percentage. The trend nationally and in ND is for more cesarean births and fewer vaginal births. Between 1998 and 2002, vaginal births decreased from 81 percent to 76 percent and cesarean births increased from 19 percent to 24 percent. Vaginal births after cesarean (VBAC) births also decreased from 31 percent in 1998 to 17 percent in 2002. In ND between 1997 and 2001, American Indian women tended to have a slightly higher percentage of cesarean births and repeat cesarean births than White women.

According to the BRFSS, twenty-seven percent of ND women age 18-44 were current smokers (smoked on one or more days in the past 30 days) in 2003. Nearly three-fourths of the current smokers indicated they smoked every day. However, the percent of women 18-44 who said they were former smokers (i.e. quit) rose from 13 percent in 2002 to 15 percent in 2003, and the percent of women who indicated they had never smoked increased from 38 percent to 59 percent.

More than 90 percent of women report participating in moderate physical activity and more than half in vigorous physical activity. However, the percent of ND women 18-44 who were overweight or obese, as measured by the BMI, increased from 30 percent in 2000 – to 41 percent in 2002 – to 45 percent in 2003.

In 2002, there were 775 primary victims and 204 secondary victims of sexual assault reported in ND. Forty percent of the primary victims were under age 18, and the majority of the primary victims were under age 30. The vast majority of victims are female and the majority of perpetrators are male.

According to the ND Council on Abused Women's Services, in 2002 there were nearly 6,000 incidents of domestic violence involving more than 4,000 new victims with more than 4,000 children directly impacted. According to Domestic Violence in North Dakota, by the Bureau of

Criminal Investigation in the Office of the Attorney General, 2,107 victims of domestic violence were reported through the ND Uniform Crime Reporting (UCR) Incident-based Reporting program. The number of incidents increased from 1,442 in 1998 to 1,835 in 2001.

Although most are White, a disproportionate number of domestic violence victims are American Indian, with a high number of incidents reported on reservations. Half of the offenders were using alcohol at the time of the incident and half of the reported domestic violence offenders were arrested. Most victims were females age 17-19. Between 1978 and 2000, half of all homicides in ND were domestic.

Domestic violence also has serious impact on children in the home. Children exposed to domestic violence are at increased risk of youth violent behavior and child abuse and neglect and are more likely to have been a victim of Shaken Baby Syndrome. There were 19 sexual assault crisis centers in ND in 2002.

Health System Capacity Indicators

The number of hospitals in the state increased from 44 in 1999 to 46 in 2003. However, during that time, the number with pediatric beds decreased from 20 to 15 hospitals and the number with obstetric services decreased from 32 to 22 hospitals. The number of hospitals in the state with Level III neonatal ICU capacity decreased from four in 1999 to three in 2003.

According to the 2000 Census, three areas of ND were designated as Metropolitan Statistical Areas (MSAs), Bismarck (including Mandan), Grand Forks and Fargo (including West Fargo). The population of these MSAs in 2000 was 284,000, or about 44 percent of the state's population. Five other areas were designated Micropolitan Statistical Areas, Minot, Wahpeton, Williston, Jamestown and Dickinson. 141,000 or 22 percent of ND's population lives in these areas. The rest of the state's population, 217,000 or 34 percent live in rural or frontier areas. Although the three MSAs contain less than half of ND's population, more than half of the state's service providers, and the vast majority of specialty care providers practice in one of the three MSAs.

In 2003, there were 288 dentists practicing in ND in 331 practice locations, up from 277 dentists in 2000. Fifty-five percent of the dentists practice in one of the three MSAs. The number of dental specialists, such as oral surgeons and orthodontists, decreased from 48 in 2000 to 43 in 2003 and the practice locations of the dental specialists decreased from 73 to 62.

The number of Family Practice physicians practicing in the state decreased from 352 in 1999 to 331 in 2002. The number of OB/GYN doctors in the state increased from 51 in 1999 to 57 in 2002. Most practice in one of the state's MSAs or five Micropolitan Statistical Areas. In 2002, all but three of the state's 86 psychiatrists practiced in Metropolitan or Micropolitan Statistical Areas. In 2003, 62 percent of the 6,500 registered nurses in the state were practicing in one of the three MSAs.

A ND Nursing Needs Study was conducted in 2002 by the University of North Dakota (UND) Center for Rural Health. Most licensed practical nurses indicated they worked in long-term care

settings and most registered nurses and advance practice nurses worked in hospital settings. Most nurses thought that the nursing supply in their patient care setting was adequate but when asked specifically about their clinical specialty, most nurses responded there was a shortage.

Family physicians provide the majority of patient care in rural areas. According to the Center for Rural Health in the UND School of Medicine, 48 percent of the residents trained in Family Practice Training Programs chose practice opportunities in ND. About forty percent of those chose a rural in-state practice, while sixty percent chose an urban in-state practice.

Forty-five percent of North Dakotans live in what are considered rural areas, with populations less than 15,000, while only 17 percent of ND physicians practice in rural areas.

There are 73 certified Rural Health Clinics (RHCs) in the state. These RHCs utilize nurse practitioners and physician assistants throughout their system. In ND, five federally funded Community Health Centers (CHCs) provide services at 13 sites. CHCs provide access to primary care, mental health and oral health services for underserved populations.

According to a 2003 publication by the Center for Rural Health at the UND School of Medicine, 83 percent of ND is designated as a primary care health professional shortage area (HPSA). Thirty percent of the state's counties are whole or partially designated dental HPSAs and 94 percent are whole or partial mental health HPSAs. Ninety-two percent of the state is designated as a medically underserved area.

The DoH administers *Women's Way*, a breast and cervical cancer early detection program for low-income women. The goal of the program is to reduce morbidity and mortality through increased screening.

Children

Demographic and Population Indicators

The number of children in the state age 1-19 decreased by more than 14,000 between 1990 and 2000. White children decreased by more than 17,000, while the number of American Indian and children of other minorities increased by more than 2,000 during the same period. The percent of ND families with children under age 18 headed by a female householder with no husband present increased from 7.1 percent in 1990 to 8.2 percent in 2000. The percent of ND children under age six living in families with both parents present and in the workforce increased from 65.5 percent in 1990 to 72.6 percent in 2000. The percent of ND children under age 18 below the poverty level decreased from 16.9 percent in 1990 to 13.5 percent in 2000. However, there are extreme disparities by race. In 2000, 10.6 percent of white children in ND were in poverty, compared to 45.8 percent of American Indian children.

During the five-year period 1997-2001, about 17 percent of ND children were receiving Food Stamps and about 29 percent received free and reduced school lunch. More than 25,000 pregnant women, infants and young children under age five and their mothers are enrolled in the ND WIC program annually. About 17.5 percent of the state's children under age 21 were

enrolled in the state Medicaid program. Sixteen percent of the state's children age three to four (3-4) received services through Head Start. There has been no significant change in annual enrollment percentages for any of these child programs over the past five years.

In 2004, the UND Center for Rural Health conducted focus group discussions with ND employers on health insurance. Participants reported that cost was the number one factor when deciding what insurance to offer their employees, followed by the type of benefits included in the coverage. Increasing insurance costs results in cost sharing and adversely impacts salaries. Many participants blamed the lack of competition in the insurance industry as the reason for increasing costs.

Health Status Indicators

During the three-year period 1999 to 2001, 149 ND children between the age of one and nineteen (1-19) died. Unintentional injuries were the leading cause of death followed by suicide (Table 3).

Table 3: Leading Cause of Death, ND Children by Age 1999-2001

	Age 1-4	Age 5-14	Age 15-19	All Ages
Unintentional Injuries	9	18	55	82
Suicide	0	5	18	23
Malignant Neoplasms	3	5	5	13
Congenital Anomalies	6	2	3	11
All Other Causes	3	9	8	20
Total	21	39	89	149

Source: CDC Wonder

Between 1997 and 2001, the ND death rate per 100,000 for children age one to four (1-4) was lower than the national rate overall and for unintentional injuries and motor vehicle accidents. However, the death rate for American Indian children in ND was substantially higher than the rate for White children (Table 4).

Table 4: Child Death Rates per 100,000 Age 1-4 US and ND by Race 1997-2001

	US Total	ND Total	ND American Indian	ND White
All Causes	34.2	28.2	41.9	19.3
Unintentional Injuries	12.3	10.0	34.9	7.9
Motor Vehicle Accidents	4.6	3.1	14.0	2.1

Source: National Center for Health Statistics

Between 1997 and 2001, American Indian children, age five to fourteen (5-14) had a higher death rate than White children. American Indian children were less likely to die as a result of unintentional injuries, but more likely to die from acute or chronic illnesses or suicide (Table 5).

Table 5: ND Child Deaths and Rates per 100,000 Age 5-14 by Race 1997-2001

	White		American Indian	
	Number	Rate	Number	Rate
Unintentional Injuries	37	9.1	3	8.0
Motor Vehicle Accidents	13	3.2	2	5.3
Acute and Chronic Illness	20	4.9	5	13.3
Suicide	6	1.5	3	8.0
Homicide	2	0.5	0	0.0
All Causes	65	16.0	11	29.2

Source: National Center for Health Statistics

For ND adolescents age 15-19, unintentional injuries were the leading cause of death, primarily in the form of motor vehicle accidents. Suicide was the second leading cause of death for this age group. American Indian teens age 15-19 have significantly higher mortality rates for all causes of death than do White teens (Table 6).

Table 6: ND Child Deaths and Rates per 100,000 Age 15-19 by Race 1997-2001

	Overall		White		American Indian	
	Number	Rate	Number	Rate	Number	Rate
Unintentional Injuries	101	37.9	85	35.5	16	97.0
Motor Vehicle Accidents	88	33.0	70	29.2	14	84.9
Suicide	33	12.4	25	10.4	8	48.5
All Causes	174	65.3	133	55.5	28	169.8

Source: National Center for Health Statistics

Although the ND rate of death due to suicide in teens age 15-19 was higher than the national rate between 1997 and 2001 (12.4 per 100,000 to 8.9), when rates are averaged over three years, the state rate has begun to show a modest declining trend since 1996 (Table 7).

Table 7: Suicide Rate for ND Adolescents Age 15-19

Years	Rate
1994-1996	22.0
1997-1999	15.7
2000-2002	8.9

According to the DHS, it is estimated that nearly 34,000, or about one in five ND children have a diagnosable mental health or addiction disorder.

- About 6,500 ND children have a serious emotional disturbance.
- More than 3,000 ND children are in need of mental health or addiction services at any given time.

In 2003, more than one in four ND high school students reported being in a fight during the last year and nearly 9 percent in a fight on school property. One in ten reported that their boyfriend or girlfriend hit, slapped or hurt them in the last year. In 2000 and 2001, more than 8,000 ND children were arrested and 6,000 were referred to juvenile court. Each year in ND, there are more than 4,000 reports of child abuse and neglect involving more than 7,000 suspected child

victims. The number of ND children affected by domestic violence has increased to nearly 5,000, more than 3 percent of all children in the state.

In 2002, the State Data Center at North Dakota State University (NDSU) conducted a statewide child abuse survey to gather public opinion about perceptions of child abuse and neglect in ND. The majority of respondents indicated that child abuse and neglect, including child sexual abuse, is a problem, but greatly underestimated the number of actual reported cases.

Health Care Access and Utilization Indicators

According to the Current Population Survey conducted by the US Census Bureau, in 2002 an estimated 11,000 children under age 18 in ND (7.4 percent) were uninsured. This estimate is substantially lower than estimates of 16 to 17 percent in the late 1990s. Seventy-four percent of children have private health insurance and most of that is employer-based. Nineteen percent of ND children have Medicaid as a source of coverage and five percent military health care.

Twenty-eight (28) percent of the uninsured children in ND are American Indian. More than 4,000 of the uninsured children live in families with incomes at 100 percent or less of the Federal Poverty Level (FPL). Another 3,000 uninsured children live in families with incomes between 126 and 185 percent of the FPL. Eighty-five percent of the uninsured children have at least one parent who works outside the home.

During CY 2003, more than 35,000 ND children under age 18 (22 percent of the state population of children < 18) were enrolled in Medicaid at sometime during the year. Two thousand three hundred (2,300) additional children were enrolled in Healthy Steps, the state's SCHIP program and an additional 625 were enrolled in the Caring program, administered by Blue Cross Blue Shield of ND for low-income children.

In 2004, the ND Medicaid program conducted a consumer survey. Of the respondents with children younger than age 21, 48.3 percent said they had completed a well child visit during the past year – up from 37.7 percent in 2002. Nearly 86 percent of the respondents who had participated in the ND Health Tracks program (EPSDT) believe the services were either very useful or somewhat useful.

According to estimates from the National Immunization Survey, a higher percentage of ND children age 19-35 months were fully immunized between 1998 and 2003 than children nationally. The percent of ND children immunized with the 4:3:1:3:3 series increased from 73 percent in 1998 to 80 percent in 2003.

Between 1999 and 2003, more than eighty percent of ND middle school students saw a dentist at some time during the year, higher than the percent for high school students. During this same time, nearly sixty percent of ND high school students reported having one or more cavities in their permanent teeth.

Health Risk Factors

The ND teen pregnancy rate has decreased from 42.4 per 1,000 in 1997 to 34.4 in 2001. Between 1997 and 2001, the state teen birth rate (per population of females age 15-19) was 30.0 compared to 49.5 for the United States overall. However, in ND, eight percent of White births were to teen mothers compared to twenty-two percent for American Indian births.

ND teen smoking rates are higher than rates for the United States overall. However, the percentage of ND high school students who are current cigarette smokers (smoked cigarettes one or more days in the past 30) decreased from 41 percent in 1999 – to 35 percent in 2001 – to 30 percent in 2003. In addition, the percent of ND teens that reported they have ever tried cigarettes has decreased from 73 percent in 1999 – to 68 percent in 2001 – to 62 percent in 2003.

The percentage of youth in grades 9-12 who are current smokeless tobacco users has declined from 15 percent in 1999 to 10 percent in 2003. Of those who had ever tried smoking, the percent of individuals who smoked their first cigarette before the age of 13 decreased from 43.7 percent in 2001 to 36.7 percent in 2003. Each year more than half of youth current smokers attempt to quit.

Although decreasing, the percentage of ND high school students who are current alcohol users (drank alcohol on one or more days in the past 30) is substantially higher than the percentage nationally. The percentage of ND high school students engaged in episodic heavy drinking (five or more drinks in a row one or more day in the past 30) was also higher than the percent nationally. In addition, more ND high school students indicated they had used alcohol or drugs the last time they had sex than students nationally (Table 8).

**Table 8: Alcohol Use: High School Students
ND and US 1999-2003**

	Current Drinker		Episodic Heavy	
	ND	US	ND	US
1999	61%	50%	46%	32%
2001	59%	47%	42%	30%
2003	54%	44%	40%	27%

According to the YRBS, the percent of ND high school students who currently use marijuana and who first tried marijuana before the age of 13 increased between 1995 and 2003.

According to the YRBS, the percent of ND high school students in grades 9-12 who were overweight – measured as $\geq 95^{\text{th}}$ percentile on the BMI – increased from 6.7 percent in 1999 to 9.3 percent in 2003. The percent was higher for males than females and the state percent was higher than the national percent. In 2003, 11 percent of ND high school students were at risk of being overweight. However, nearly one-third (32.3) thought they were overweight and nearly half (45.9 percent) were trying to lose weight. Between 1999 and 2003, more than twice as many ND girls were trying to lose weight than boys.

The percent of children between the age of two and five (2-5) in the ND WIC program who are overweight increased between 1993 and 2003. The rate among American Indian children is nearly twice that for Caucasian children.

One in six (16 percent) of ND sixth graders are overweight. More boys are overweight than girls and sixth graders living in rural areas are more likely to be overweight than those living in urban areas. Nearly one-third of ND sixth graders are physically inactive 1-2 hours each day and 15 percent are inactive more than two hours each day.

The number of ND high school students that reported having ridden with someone who had been drinking (one or more times in the past 30 days) and having driven when they had been drinking (one or more times in the past 30 days) is higher than high school students nationally (Table 9).

Table 9:

	Rode w/ Drinker		Drove When Drank	
	ND	US	ND	US
1999	48%	33%	31%	13%
2001	44%	31%	27%	13%
2003	43%	28%	27%	11%

According to ND Vehicle Crash Facts-2000 by the ND DOT, there were 36 motor vehicle fatalities to children age 17 and younger between 2000 and 2002. In 24, or two-thirds of those, the victim was not wearing safety equipment such as a seat lap or shoulder belt.

In 2003, half of ND students in the eleventh grade and 64 percent of those in the twelfth grade reported having had sexual intercourse at least once during their lifetime. One third of ND students in grades 9-12 reported using alcohol or drugs before sexual intercourse, compared to 25 percent nationally. Of the students who had sexual intercourse during the past three months, two-thirds indicated they used a condom. The number of reported cases of Chlamydia in ND teenagers age 15-19 has nearly doubled between 1997 and 2003.

Health System Capacity Indicators

In 2002, there were nearly 5,000 students for every school nurse in ND, substantially higher than the ratio of one nurse for every 750 students as recommended by the National Association of School Nurses.

According to ND Kids Count in 2000, 81 percent of ND women with children under 18 years of age were in the workforce. ND has the second highest proportion in the nation of women with young children (age 0-5) in the workforce, at 72.6 percent. Although there were nearly 2,800 child care providers in the state in 2003, licensed child care is available to only about one-fourth of all children age zero to thirteen (0-13) (the age group potentially in need of care).

Child care was the tenth largest occupation in ND in the 2000 Census. Between 1990 and 2000, the percent of North Dakotans in the child care workforce remained relatively unchanged, while the need for child care has increased. The proportion of families with children under the age of 18 headed by a single parent increased by 31 percent during the same time period in the state.

In 2002, there were 79 pediatricians practicing in ND. Three-fourths of them practiced in one of the state's three MSAs.

The ND American Indian Training Institute, in collaboration with the four reservations in ND, provides culturally relevant training and curriculum packages for professionals working with American Indian children and families.

County social services offices administer child welfare services and economic assistance, including the Medicaid program. The NDSU Extension Service provides information and education about nutrition, health and fitness. They publish and distribute children's books about food, eating and health including cholesterol guidelines for children, child development and parenting.

Children with Special Health Care Needs

Demographic and Population Indicators

According to the SLAITS CSHCN survey, 12.4 percent of ND children are considered to have a special health care need.

According to estimates from the 2000 Census, 5.6 percent of ND children age five to fifteen (5-15) have a disability. Most have a mental disability and less than one percent have a sensory or physical disability or a disability in the area of self-care. A higher percentage of American Indian children in ND have a disability (6.5 percent) than White children (5.4 percent). In 2003, 812 ND children under age 16, and 940 children under age 18 were receiving Supplemental Social Security (SSI) benefits.

The number of children served by the state CSHCN program declined from 1,799 in FY 1998 to 1,372 in FY 2004. In FY 2004, 211 children received treatment services and 107 received diagnostic services (down from 174 in FY 2000). Eight hundred and forty nine (849) children were served through 30 multidisciplinary clinics and 271 through contracted services. During the five-year period FY 1998-2002, 10.5 percent of the children served by CSHS were American Indian, compared to an estimated statewide American Indian child population of eight percent.

Health Status Indicators

According to the Diabetes Control Program in the DoH, in 1998 it was estimated about 250 children age 0-19 in ND had diabetes: a rate of 2.9 per 1,000 children. In a 2004 study conducted by the DoH, three in 1,000 ND children enrolled in Blue Cross Blue Shield of North Dakota had diabetes. Ninety-five percent of those children use insulin, and treatment, measured by specific standards of care, had improved between 1999 and 2002. The study also found that children with diabetes experience more complications and have more hospitalizations and emergency visits than children without diabetes.

According to a state-added childhood asthma module to the 2002 BRFSS, 12.7 percent of respondents indicated they had one or more children in their household who had ever been diagnosed with asthma. Over seventy five and one-half (75.6) percent of them indicated those children still have asthma for an estimated effective prevalence rate of 9.6 percent. A study conducted by the DHS found that 8.3 percent of ND children in the ND Medicaid program had a diagnosis of asthma as indicated on a health care claim form. This study found American Indian children and males had higher rates of asthma than White children and females.

Excluding admissions for newborn delivery, between 2002 and 2003 there were nearly 4,000 inpatient hospitalizations among ND Medicaid children under age 18. The leading causes of hospitalization were mental and behavioral disorders, followed by respiratory diseases, and other infections, diseases and illness.

Health Care Access and Utilization Indicators

During the five-year period 1996-2000, approximately 1,600 or one percent, of ND children under age 18 received Supplemental Security Income (SSI) benefits. About two percent of American Indian children received SSI. Although they comprise eight percent of the state's child population, 15 percent of all SSI recipients were American Indian.

In FY 2003, 1,670 ND children received services through the state's Vocational Rehabilitation program. This comprises approximately three percent of the state's population of 15-19 year olds. The leading diagnostic eligibility categories were learning disabilities, mental retardation, mental illness and alcohol and drug dependence.

More than 13,000 ND children age 3-21 are served each year through special education. The most common eligibility categories are learning disabilities and speech/language impaired. Between the December 1998 and December 2002 child counts, the number of children eligible for special education with autism increased from 96 to 197. The number of children eligible under the other health impaired category and the emotionally disturbed category doubled.

ND's Early Intervention system serves children age birth to three with or at risk for developmental delay. Eligibility is based on four criteria: a 25 percent delay in two or more areas of development, a 50 percent delay in one area of development, a high risk diagnosis, or informed clinical opinion. The number of children served through Early Intervention increased from 251 in 2001 to 389 in 2003. Between July 2002 and June 2003, Right Track staff completed 4,852 home-based developmental screenings.

In 2003, Family Voices of ND, Inc. conducted thirty in-person or phone interviews with families of CSHCN in ND. Two-thirds said that health care services were working for their child. Program changes were the main reason given by the one-third that said services were not working for their child. Seventy-six (76) percent reported issues with special education, such as unhappiness with their child's Individual Education Program (IEP), feeling misunderstood as parents and struggling to obtain needed services. Only thirteen percent reported being told about other services for them or their child when applying for public assistance. Just one-third of respondents knew about the state's SCHIP plan. Ninety-three percent said they did not fully

understand their child's health plan. All of the families surveyed indicated they would have liked to know what other services were available and needed assistance in negotiating various systems.

According to the 2002 SLAITS CSHCN survey, 62 percent of families felt they had adequate private and/or public insurance to pay for the services they need. Eighty-eight percent of ND CSHCN indicated they have a usual source of health care. Of those, an equal number said their source was either a doctor's office or a clinic. Eighty-nine percent of ND CSHCN indicated they had a personal doctor. Of those, 40 percent of the personal doctors were general doctors and one-third pediatricians.

In FY 2003, ninety-four percent of the children served by the state CSHCN program had a source of health insurance, up from 85 percent in 1998. Three-fourths of those were covered by private insurance and one in six (16 percent) by Medicaid. Two percent of the children were covered by Healthy Steps, the state's SCHIP plan.

Health Risk Factors

The rate of selected birth defects in ND during the five-year period 1997-2001 was statistically comparable to 1999 rates from the Metropolitan Atlanta Congenital Defects Program.

The percent of ND newborns screened for hearing impairments at hospital discharge increased from thirty-nine percent in 1998 to more than ninety-five percent in 2003.

Virtually 100 percent of babies born in ND are screened for metabolic diseases. Currently, ND screens for 39 separate conditions. All newborns suspected or confirmed to have one of the diseases are offered referral and follow up.

The percent of Medicaid eligible children under age one in ND receiving an initial or periodic screening increased from 54 percent in 1998 to 71 percent in 2002.

Impact on Children and Families

According to the National SLAITS CSHCN Survey, four percent of CSHCN in ND have needs that change all the time and one in seven (13 percent) report their child's condition has greatly affected their ability. Nine percent of CSHCN's missed more than ten school days last year due to an illness or injury.

More than one in five families of CSHCN in ND indicated their child's health problems have caused financial problems for them. One in six (15.7 percent) needed additional income to pay for their child's medical expenses.

Of the families served by the state CSHCN program, more than two-thirds indicated they paid co-pays out of pocket during the past year and more than half paid costs for deductibles, medicine/prescriptions, or insurance premiums.

Health System Capacity Indicators

The ND CSHCN program funded six focus groups across the state to assess issues affecting children with special health care needs and their families. Following are key findings from those focus groups.

- Families are often confused and frustrated about where to get information about the services available for their child.
- Many expressed feelings of being “stressed” or “burned out” with the responsibility of caring for their child.
- They are generally pleased with the care provided by health care professionals, but there is often a lack of coordination among the different providers.
- Health care professionals sometimes overlook the contributions parents can have in planning for their child.
- When seeking financial assistance for their child, families expressed frustration with paperwork requirements, that assistance continued to be cut, and felt being “looked down upon” by people who administer the programs. Some said they don’t seek assistance because the process is too difficult or degrading.
- Some American Indian families felt their unique cultural needs and concerns were not being addressed.
- Families need more respite care from qualified, well-trained providers.

The number of pediatric sub-specialists in the state has decreased from 48 in 1999 to 44 in 2002. Eighty-four percent practice in one of the state’s three MSAs and more than half (25) practice in Fargo. In 2002, there were 466 physical therapists practicing in ND. Approximately half of ND’s child population lives in urban areas, but more than 60 percent of the physical therapists (286) practice in urban areas.

The ND Partnerships Program offers case-aides, care coordinators and other intensive in-home family preservation services for children with severe emotional disorders. The ND chapter of the Federation for Children’s Mental Health provides support and information for children and youth with emotional, behavioral or mental disorders and their families. The ND Protection and Advocacy Project advocates for and protects the legal rights of people with disabilities. Eight regional human service centers offer developmental disabilities, child welfare and children’s mental health services. The state’s Developmental Center provides services to individuals with developmental disabilities/mental retardation and the State Hospital provides specialized psychiatric and substance abuse services.

Five of the six national goals for CSHCN were measured through the SLAITS CSHCN survey. ND compared favorably for each of the measures with the exception of transition (Table 10).

Table 10: National Goals for CSHCN

	ND	US
1. Partnership in decision-making and satisfaction with services Components: Doctors make family feel like a partner (86 percent) Families are satisfied with services received (64 percent)	61.5%	57.5%
2. Adequate insurance to pay for the services they need Components: Child has public or private insurance (95%) No gaps in coverage during the year (87%) Insurance usually or always meets child's needs (89%) Costs not covered are reasonable (72%) Insurance permits child to see needed providers (92%)	62.0%	59.6%
3. Care within a medical home Components: Usual source of sick or preventive care (88%) Personal doctor or nurse (89%) No problems getting referral when needed (81%) Effective care coordination when needed (44%) Receive family-centered care (71%)	54.7%	52.6%
4. Service system is organized for easy use Components: Services are usually or always organized for easy use (83%)	83.4%	74.3%
5. Receive services necessary to make transitions to adult life Components: Received guidance and support in transition (13%) Doctors talked to them about changing needs (55%) Have a plan for addressing changing needs (58%) Doctors have discussed shift to adult provider (34%) Have received vocational or career training (29%)	3.3%	5.8%

Following is a PowerPoint presentation summarizing Title V needs assessment data used at a two-day planning retreat held in October 2004:

Maternal and Child Health (MCH) Children's Special Health Services (CSHS) Planning Retreat

October 28, 2004
Pioneer Room
ND State Capitol
Bismarck, ND

Maternal and Child Health Population Top 5 Health Issues From Participant Survey

1. Inadequate insurance coverage (25)
2. Lack of knowledge about resources & programs (22)
3. Access to dental care (21)
4. Lack of health insurance (17)
5. Poverty/income (17)
6. Access to mental health services (17)

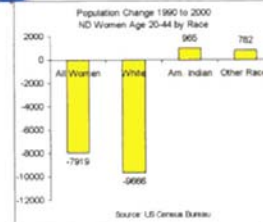
Why Are We Here?

"The State must prepare a statewide needs assessment every 5 years that shall identify (consistent with health status goals and national health objectives) the need for:

- Preventive and primary care services for pregnant women, mothers and infants;
- Preventive and primary care services for children, and;
- Services for CSHCN

Title V of the Social Security Act
Section 505 (a)(1)

Population Changes: Females



The population of women age 20-44 decreased by nearly 8,000 between 1990 and 2000 in ND. The population of White women decreased by nearly 10,000 while the population of women who are American Indian or of other races increased.

Maternal and Child Health Population

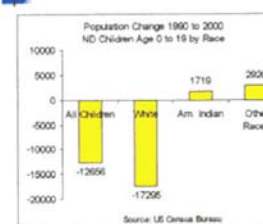
How Will We Do This?

Review and study the data that tells us about the health of the maternal and child health population in North Dakota.

Use this information to help identify which are the most important priority health needs.

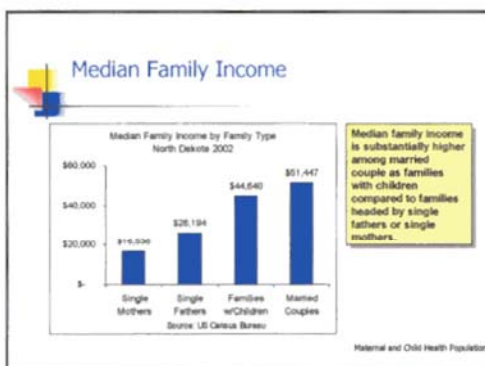
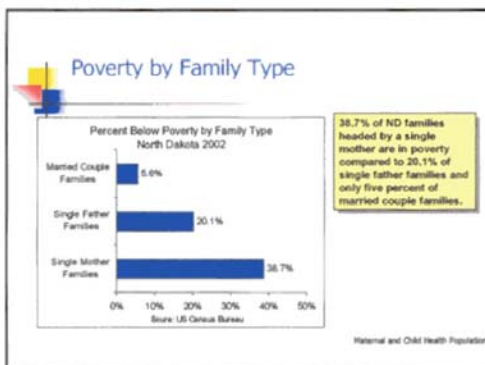
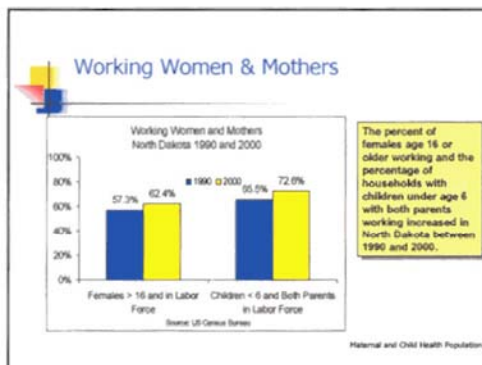
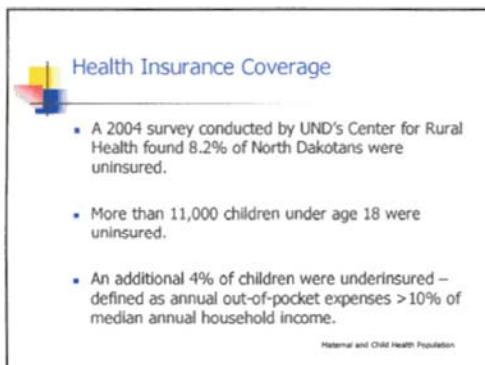
Discuss ways in which we can work together to improve the health of the MCH population.

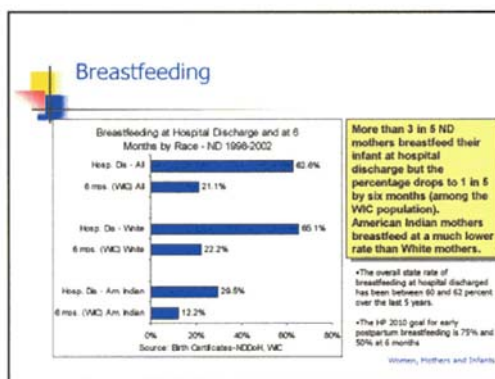
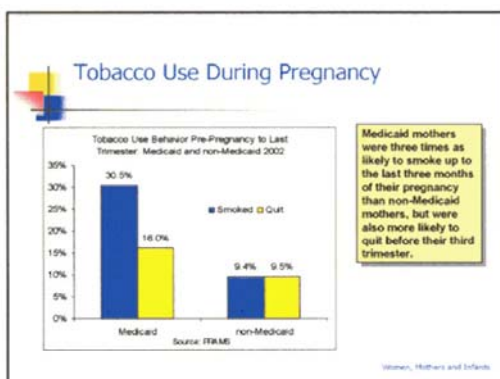
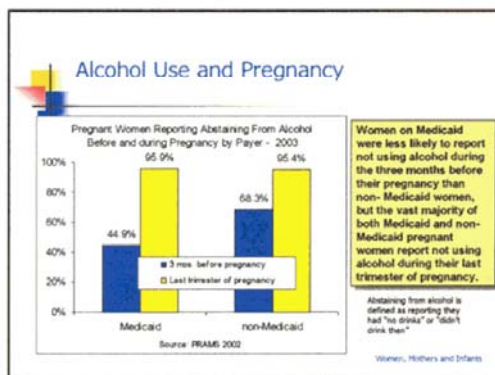
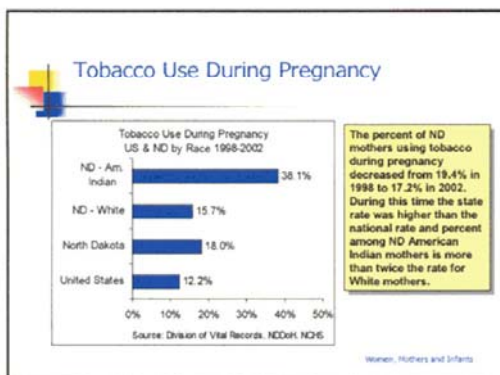
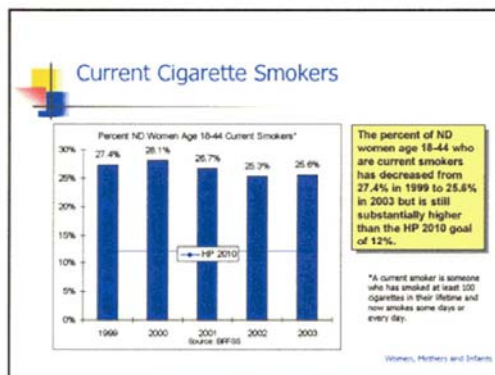
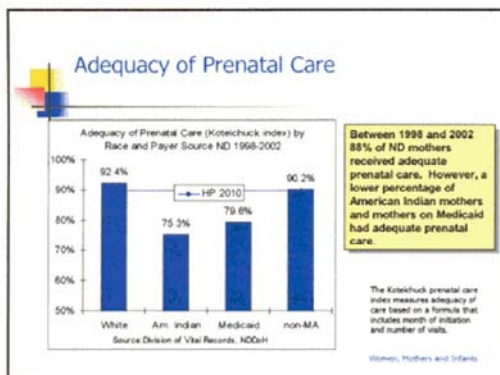
Population Changes: Children

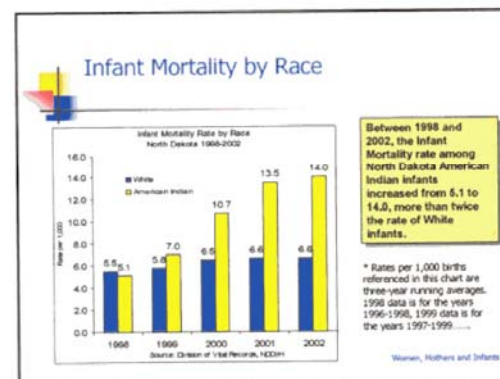
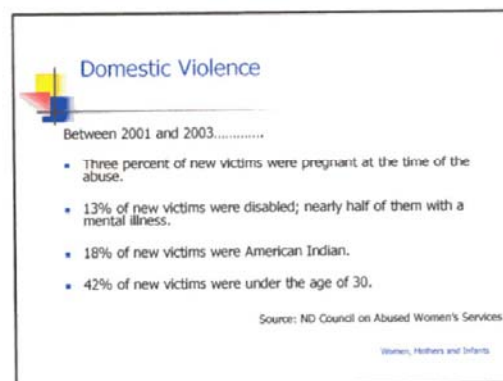
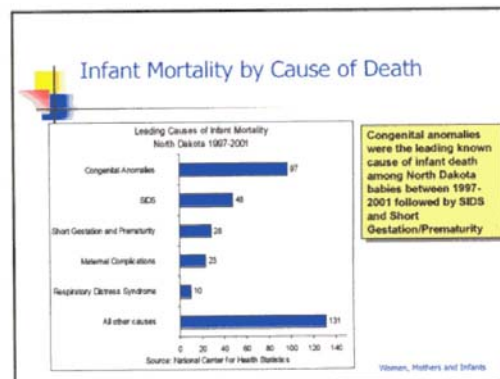
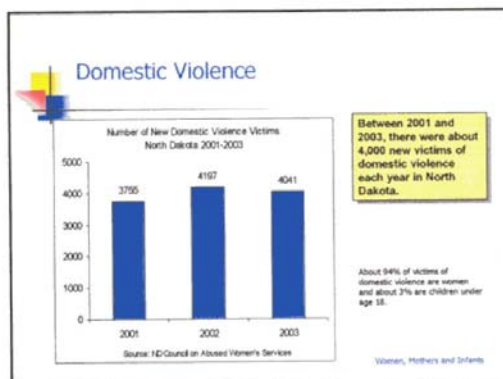
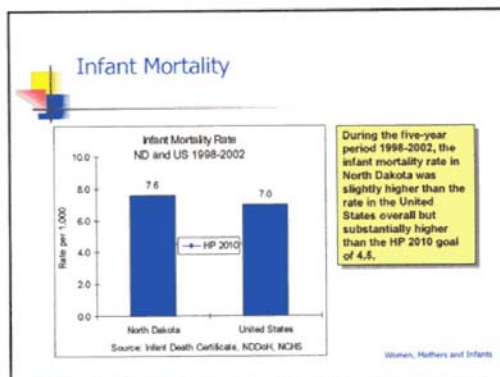
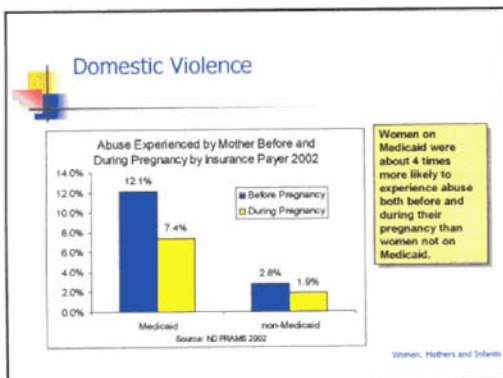


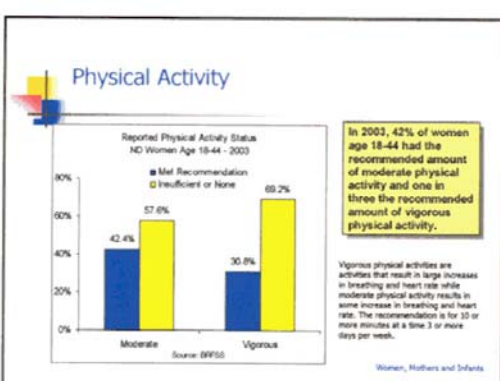
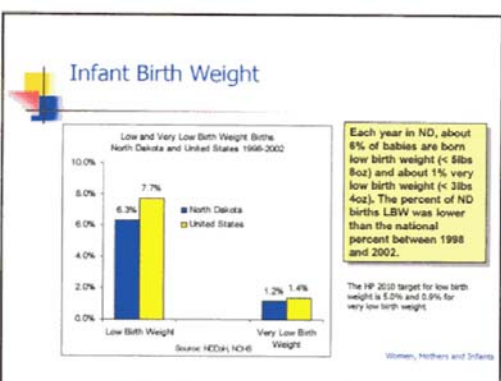
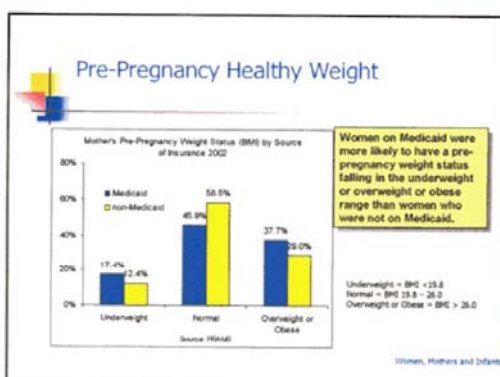
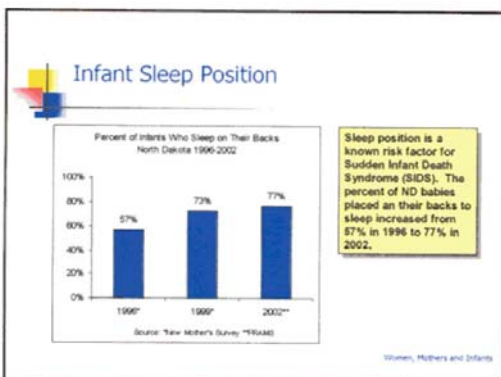
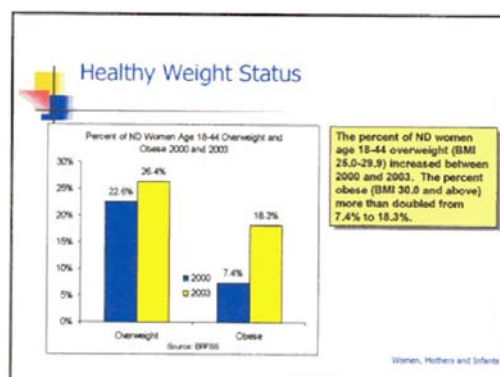
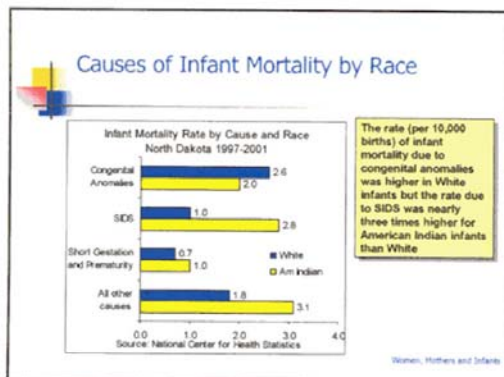
The population of children age 0 to 19 in ND decreased by more than 12,500 between 1990 and 2000. The number of White children declined by more than 17,000 while the population of minority children increased by nearly 5,000.

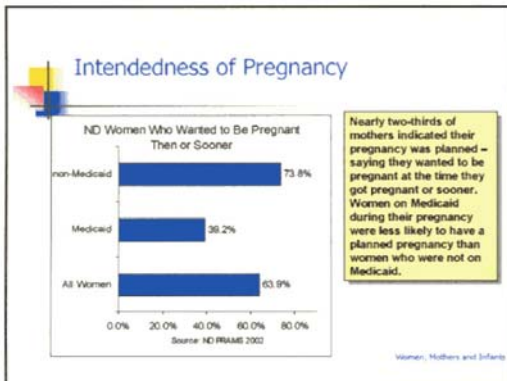
Maternal and Child Health Population







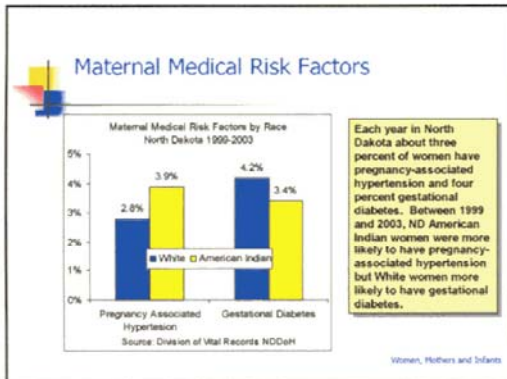




Children and Adolescents

Population group definition:

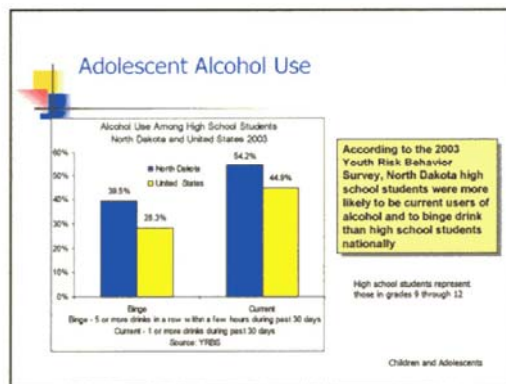
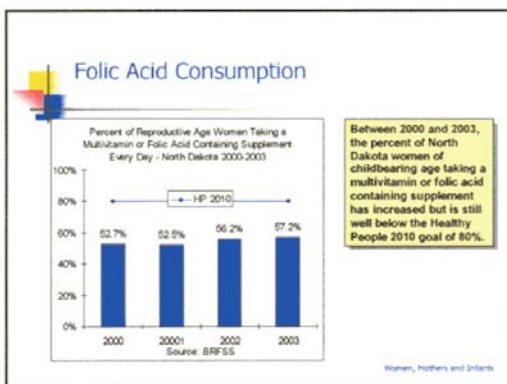
- Children age 1 up to age 18.

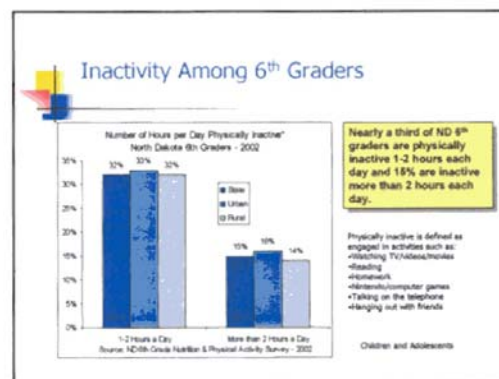
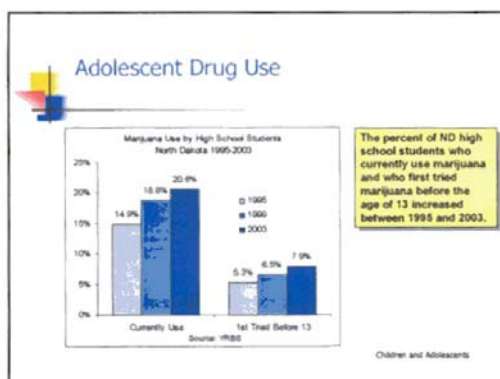
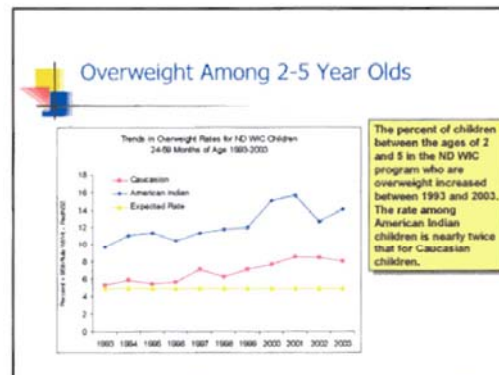
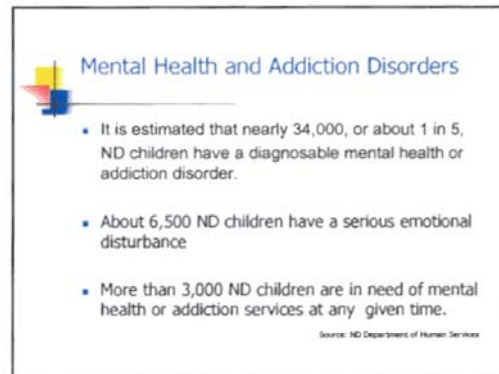
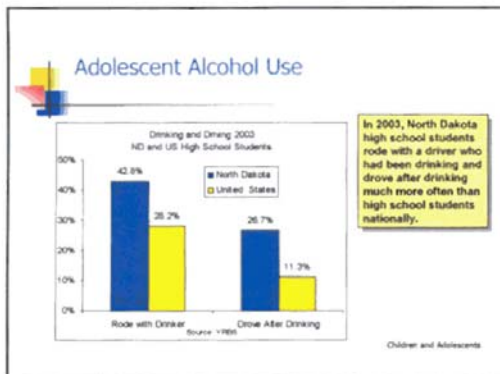


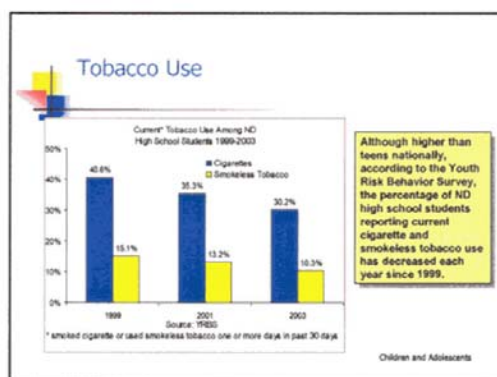
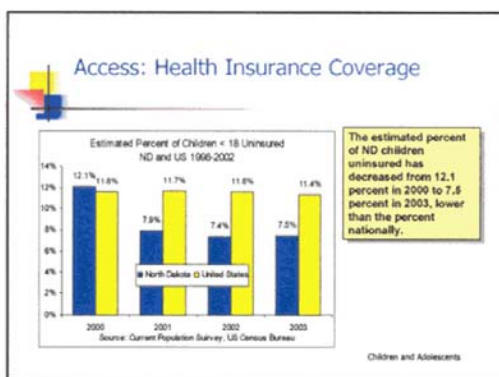
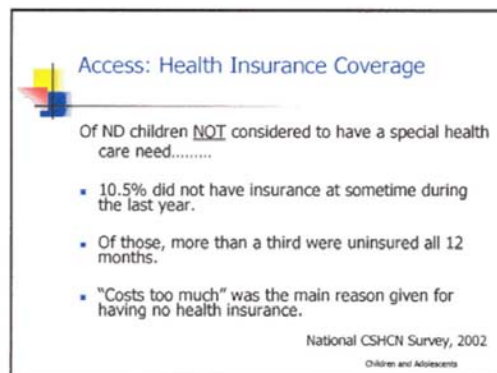
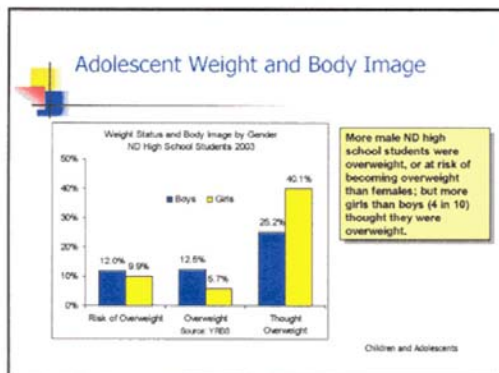
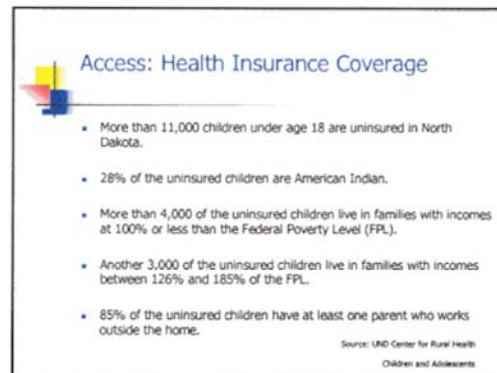
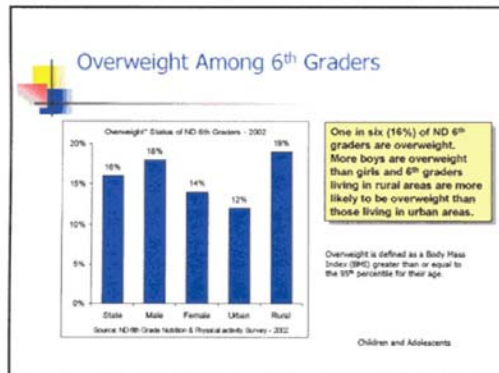
Retreat Participant Survey Results

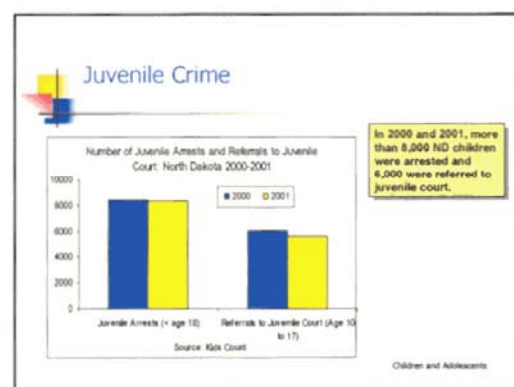
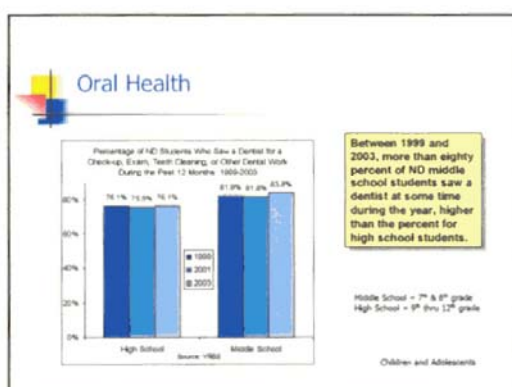
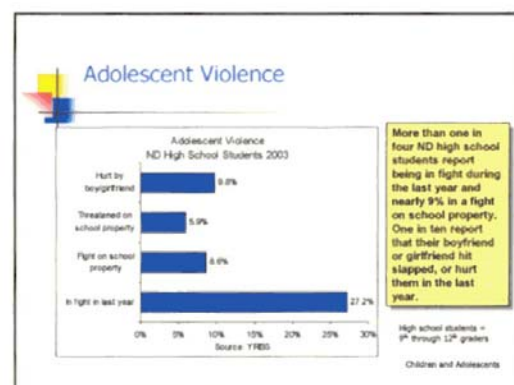
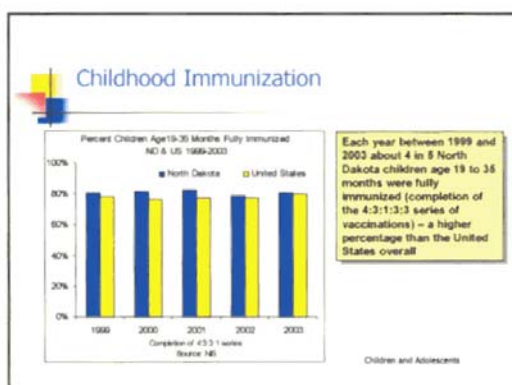
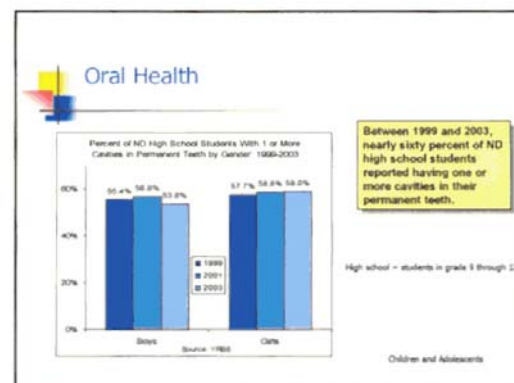
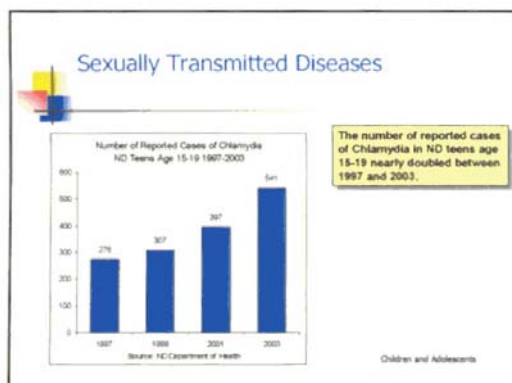
Top 5 Health Issues Affecting Children and Adolescents in North Dakota

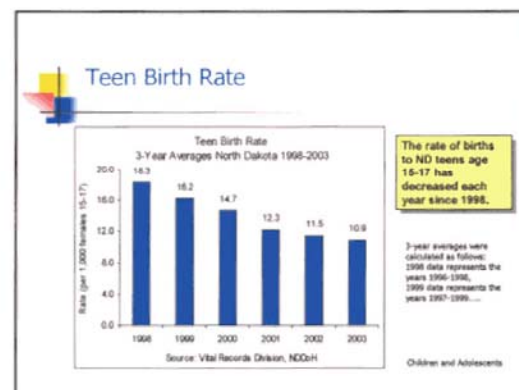
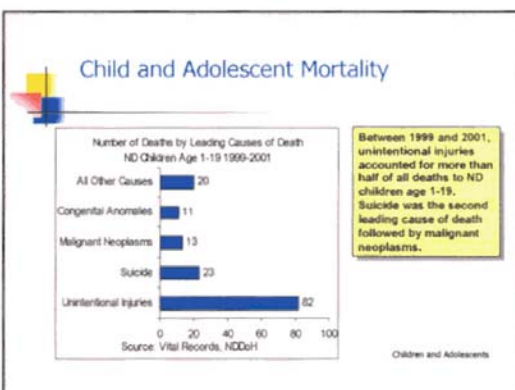
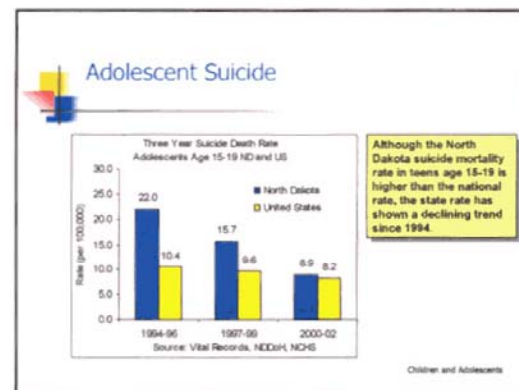
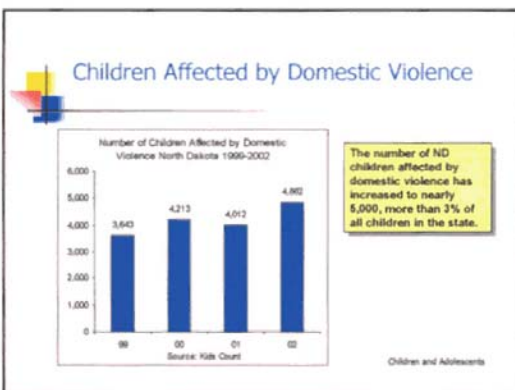
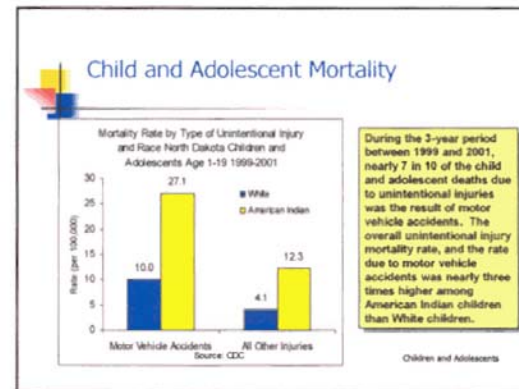
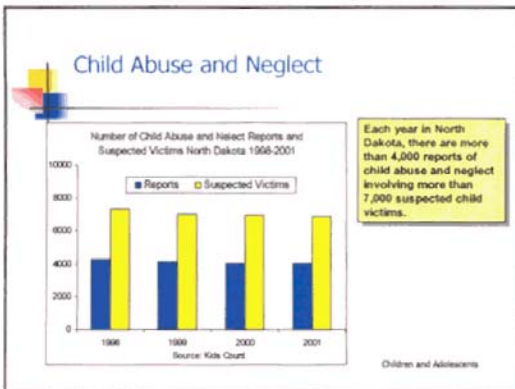
1. Adolescent drug & alcohol use (28)
2. Healthy weight (27)
3. Access to health care (24)
4. Adolescent tobacco use (16)
5. Youth violence/bullying (15)

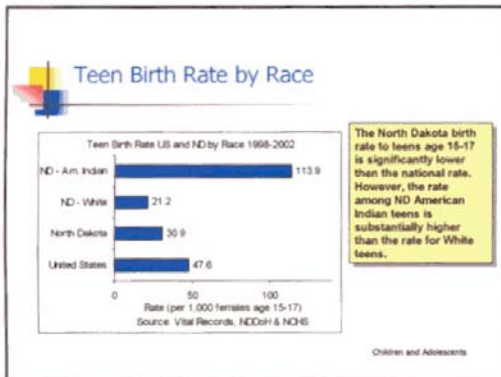




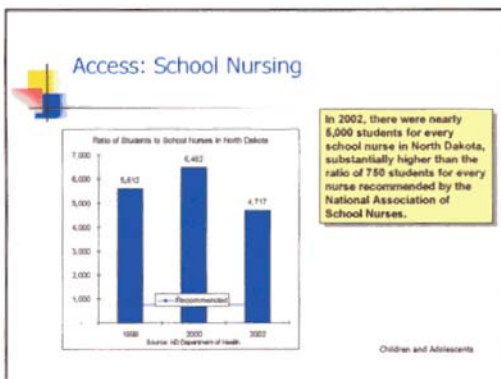








- ### Top 5 Health Issues From Participant Survey
1. Availability of specialists (23)
 2. Impact on families (21)
 3. Lack of support/ancillary services (20)
 4. Transition to adulthood (16)
 5. Lack of screening programs and early intervention services (16)
 6. Family participation/involvement (16)
- Children with Special Health Care Needs



- ### Indicators
- Health status
 - Health care access
 - Screening and early detection
 - Impact on families
 - Health system – national core measures
- Children with Special Health Care Needs

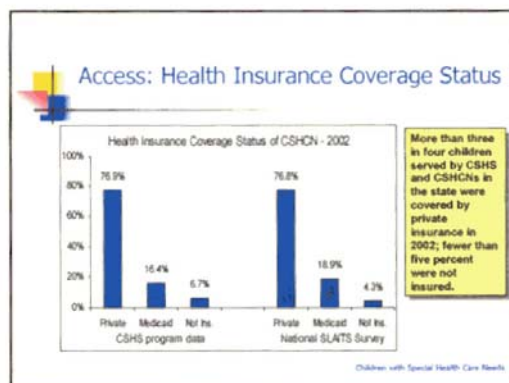
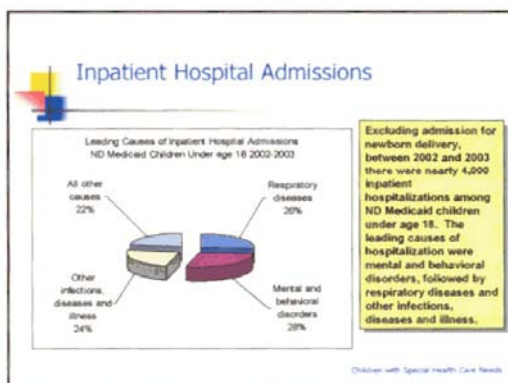
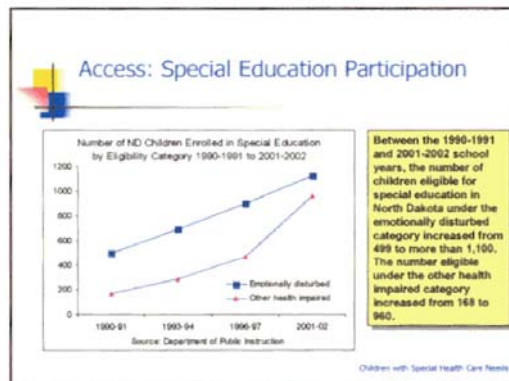
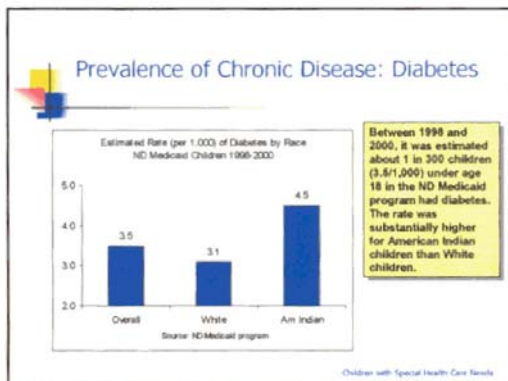
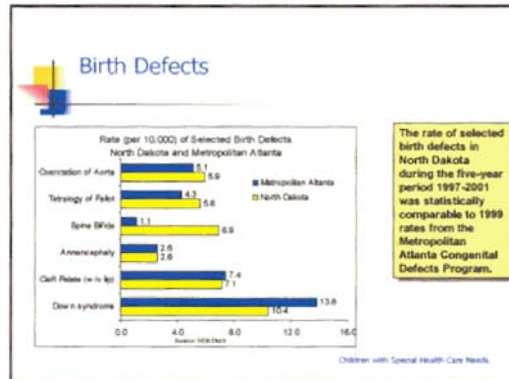
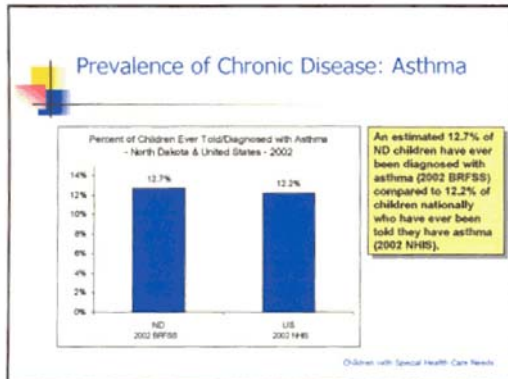
Children with Special Health Care Needs

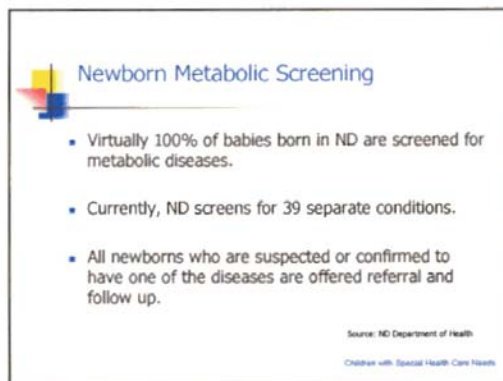
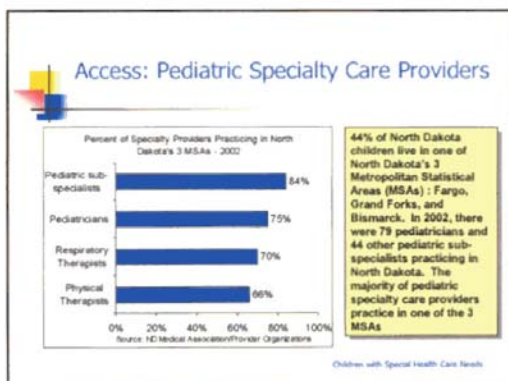
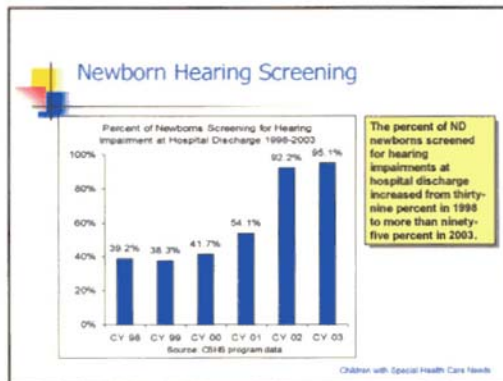
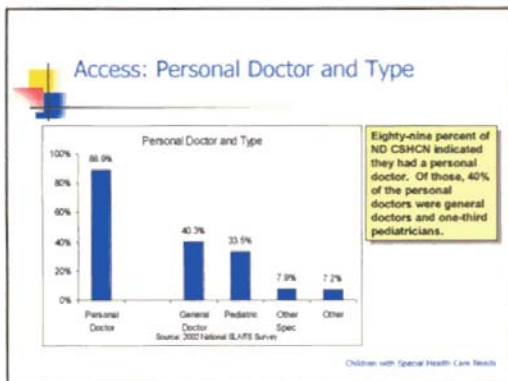
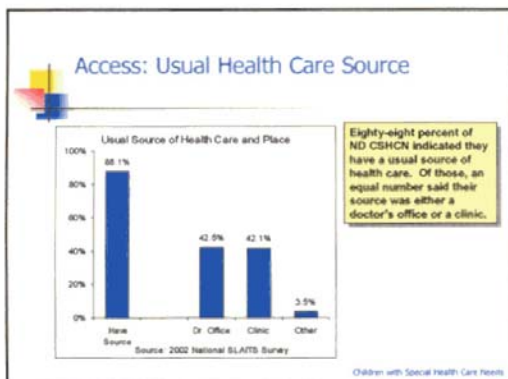
Population group definition:

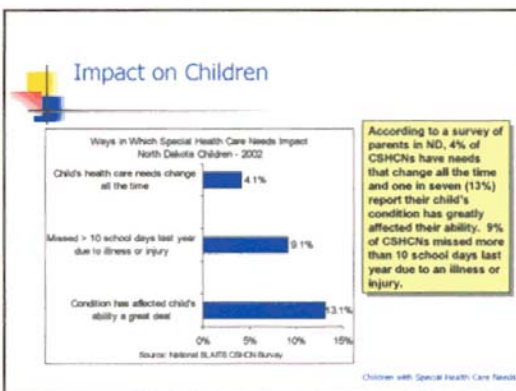
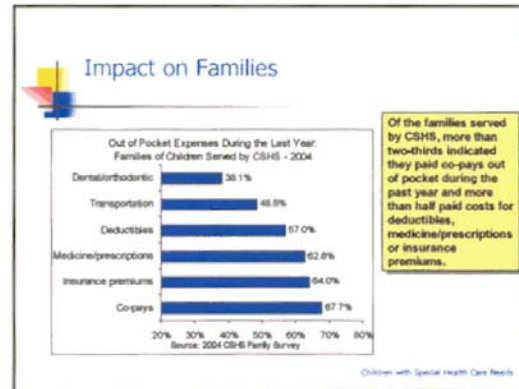
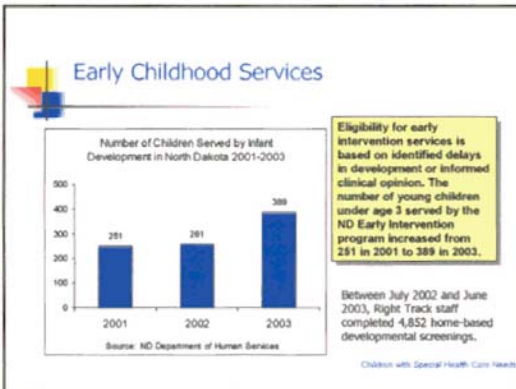
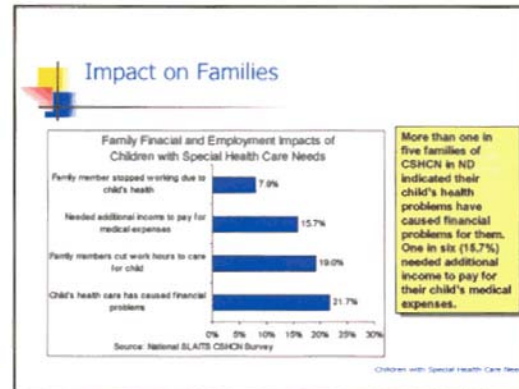
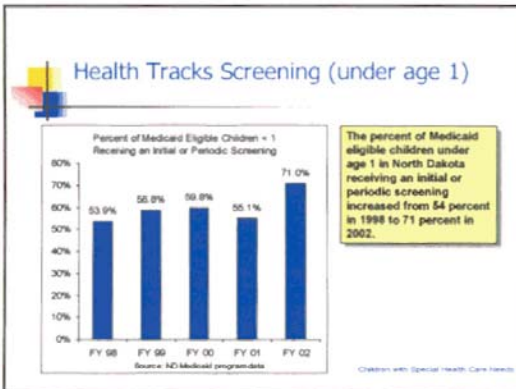
Children with special health care needs (CSHCN) are those who have or are at risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

Maternal and Child Health Bureau, 1997









Core National Outcomes

- Medical home
- Family participation in decision-making
- Adequate insurance
- Service system organization
- Transition to adult life
- Screening

Children with Special Health Care Needs

Adequate Insurance

Percent of CSHCN with Adequate Insurance to Pay for the Services They Need - ND & US 2002

Location	Percent of CSHCN with Adequate Insurance
North Dakota	82.0%
United States	58.6%

Source: National SLAITS CSHCN Survey

Components:

- 98% of child have public or private insurance.
- 87% had no gaps in coverage during the year.
- 89% feel insurance usually or always meets child's needs.
- 72% feel costs not covered are reasonable.
- 82% have insurance that permits child to see needed providers.

Children with Special Health Care Needs

Medical Home

Percent of CSHCN Who Receive Care in a Medical Home - ND and US 2002

Location	Percent of CSHCN Who Receive Care in a Medical Home
North Dakota	54.7%
United States	52.6%

Source: National SLAITS CSHCN Survey

Components:

- 88% have a usual source of sick and preventive care.
- 89% have a personal doctor or nurse.
- 81% have no problems getting referral when needed.
- 44% receive effective care coordination when needed.
- 71% receive family-centered care.

Children with Special Health Care Needs

Service System Organization

Percent of Families of CSHCN Who Indicate the Service System is Organized for Easy Use - ND & US 2002

Location	Percent of Families of CSHCN Who Indicate the Service System is Organized for Easy Use
North Dakota	83.4%
United States	74.3%

Source: National SLAITS CSHCN Survey

Component:

- 83% feel services are usually or always organized for easy use.

Children with Special Health Care Needs

Family Participation in Decision-Making

Percent of CSHCN Whose Families Participate in Decision-Making About Their Child's Care - ND & US 2002

Location	Percent of CSHCN Whose Families Participate in Decision-Making
North Dakota	61.5%
United States	57.5%

Source: National SLAITS CSHCN Survey

Components:

- 86% say doctors make the family feel like a partner.
- 64% of families are satisfied with services received.

Children with Special Health Care Needs

Transition to Adult Life

Percent of CSHCN Receiving Services Necessary to Make Transitions to Adult Life - ND & US 2002

Location	Percent of CSHCN Receiving Services Necessary to Make Transitions to Adult Life
North Dakota	3.3%
United States	5.8%

Source: National SLAITS CSHCN Survey

Components:

- 13% of children have received guidance and support in the transition to adulthood.
- 55% have had doctors talk to them about changing needs.
- 58% of children have a plan for addressing changing needs.
- 34% report doctors have discussed shift to adult provider.
- 29% of children have received vocational or career training.

Children with Special Health Care Needs

What Families of CSHCN Say

- Families are often confused and frustrated about where to get information about the services available for their child.
- Many expressed feelings of being "stressed" or "burned out" with the responsibilities of caring for their child.
- They are generally pleased with the care provided by health care professionals but there is often a lack of coordination among the different providers.
- Health care professionals sometimes overlook the contributions parents can have in planning care for their child.

Source: CSHS Needs Assessment: Agency HANU
Children with Special Health Care Needs



What Families of CSHCN Say

- When seeking financial assistance for their child, families expressed frustration with paperwork requirements, that assistance continued to be cut, and felt being "looked down upon" by people who administer the programs. Some said they don't seek assistance because the process is too difficult or degrading.
- Some Native American families felt their unique cultural needs and concerns were not being addressed.
- Families need more respite care from qualified, well trained providers.

Source: CSHS Needs Assessment: Agency HANU
Children with Special Health Care Needs

Children with Special Health Care Needs Priority Needs

List the health need that is most important in this box			
List the 2 health needs that are 2nd most important in these boxes			
List the 3 health needs that are 3rd most important in these boxes			


What Pediatric Providers Say

- Less than one-fourth thought the availability of resources in their community to meet the needs of CSHCN was "very good" or "excellent"; nearly half thought it was "fair" or "poor".
- Lack of awareness about available services and lack of adequate insurance coverage were their two most common barriers to providing services to CSHCN.
- Lack of a coordinated funding system and fragmentation of services were the two most common systems barriers identified.
- Respite care or other family support services and mental health services were the two most common services mentioned lacking within their community.

Source: CSHS Needs Assessment: Agency HANU
Children with Special Health Care Needs

Children and Adolescents Priority Needs

List the health need that is most important in this box			
List the 2 health needs that are 2nd most important in these boxes			
List the 3 health needs that are 3rd most important in these boxes			



Women, Mothers, and Infants Priority Needs

List the health need that is most important in this box			
List the 2 health needs that are 2nd most important in these boxes			
List the 3 health needs that are 3rd most important in these boxes			

4. Examine MCH Program Capacity by Pyramid Levels

Please see Section 3, Needs Assessment of the MCH Population Groups, for discussion of MCH Program Capacity by Pyramid Levels.

5. Selection of State Priority Needs

More than forty Title V staff and state and community partners and stakeholders attended the retreat. The retreat facilitator led participants through a need prioritization process organized within three MCH Population groups: women, mothers and infants, children and adolescents, and children with special health care needs. Each group identified priority needs, but were unable to rank them according to importance. The women, mothers and infants group identified 12 needs, the children and adolescents group 11 needs, and the children with special health care needs group 13 needs. Each group then wrote specific need statements for each of the priority needs.

Following is a list of the priority needs:

Children and Adolescents

- To increase physical activity among pre-school and school-age children
- To reduce the rate of intentional and unintentional injury among children and adolescents
- To improve early intervention for children with mental health and substance abuse disorders
- For children with mental health and substance abuse disorders to receive appropriate treatment
- To reduce marijuana use among children and adolescents
- To reduce the rate of underage drinking
- To reduce exposure to second hand smoke among children and adolescents
- To reduce tobacco use among children and adolescents
- To increase the percent of healthy weight among children and adolescents
- To reduce the number of teens engaging in sexual activity
- To improve access to health care (i.e. dental, mental health, school health)

Women, Mothers and Infants

- To increase access to dental services for low-income women
- To improve early intervention of mental health and substance abuse disorders in women
- To increase physical activity among women
- To increase healthy weight among women
- To improve early access to prenatal care among low-income populations
- To increase the initiation and duration of breastfeeding
- To decrease the rate of SIDS among American Indians
- To increase the number of women consistently screened for domestic violence
- To increase access to screening for mental health and wellness of infants
- To increase access to preventive care

- To reduce tobacco use among all women of child bearing age
- To increase the rate of pregnancies that are intended

Children with Special Health Care Needs

- To reduce the incidence of diabetes among children
- To reduce the percent of inpatient hospitalization due to mental health and behavioral disorders among children
- To improve/increase geographic access to pediatric specialty care providers
- To improve access to children's mental health services
- To improve the capacity to monitor newborns diagnosed with hearing loss
- To reduce the impact of chronic health conditions on children
- To reduce the impact of chronic health conditions on families
- To reduce family financial hardship due to child's health care expenses
- To increase care coordination within medical homes
- To increase transition services for youth with special health care needs
- To increase the availability of family support services – including quality respite and child care.
- To improve cultural competence in the service delivery system
- To increase information and awareness about available services

After the retreat, three small workgroups were formed for each of the three population groups. Workgroup members consisted of Title V staff with programmatic expertise about specific needs as well as outside stakeholders. Workgroup members worked through a process designed to sort the priority needs for their population group into one of three lists based on the following criteria:

A List: This is a developmental need. It's a priority, but we need to get more information or research intervention strategies.

B List: This priority need is already addressed through of the 18 federal performance measures OR it is something we are already doing and will continue to do (e.g. mandated programs/grants)

C List: All of the other priority needs not on the A or B List.

For those left on the C List we asked the following questions:

- Can we collaborate with someone else who has primary responsibility for the priority need (e.g., *HND*)?
- Do we have the resources needed to address the priority need?
- Do we know if there are effective interventions?
- Do we have baseline data and can we track improvement?

Based on the answers to these questions, we decided:
Should this be one of the 7-10 state performance measures?

Based on this criteria, ten priority needs were selected which were chosen for the ten state “negotiated” performance measures for the next five-year grant cycle. Those ten priority needs and performance measures are:

Priority Need Statement	State Performance Measure
To increase physical activity and healthy weight among women.	#S1: The percent of healthy weight among women age 18-44.
To increase the initiation and duration of breastfeeding.	#S2: The percent of women breastfeeding their infants at six months or longer.
To increase access to dental services for low-income women.	#S3: The percent of women age 18-44 enrolled in Medicaid who receive a preventive dental service.
To increase access to preventive health services for women.	#S4: The degree to which women age 18-44 have access to preventive health services as measured by 5 indicators of health care access.
To reduce the rate of intentional and unintentional injuries among children and adolescents.	#S5: The rate of deaths to children age 1-19 caused by intentional and unintentional injuries per 100,000 children.
To increase physical activity among pre-school and school-age children.	#S6: The percent of children age 6-17 who exercised or participated in a physical activity that made him/her sweat and breathe hard, such as basketball, soccer, running, or similar aerobic activities on 5 or more days during the past week.
To increase the percent of healthy weight among children and adolescents.	#S7: The percent of ND children age 2-17 with a BMI in the normal weight range.
To reduce the impact of chronic health conditions on children.	#S8: The degree to which the state can assess and plan for the health and related service needs of children with extraordinary medical needs.
To improve geographic access to pediatric specialty care providers.	#S9: The percent of families who reported they “had no problem at all” in getting care for their child from a specialist doctor.
To increase information and awareness about available services.	#S10: The percent of activities completed in the CSHS Public Information Services plan.

After the selection of the state's 10 priority needs and development of state-negotiated performance measures, individual staff persons from the MCH program were assigned primary responsibility for each national and state performance measure that closely related to their programmatic area of expertise. CSHS program staff opted to work on CSHCN related performance measures as a group. The SSDI coordinator, who works with both Title V programs, was responsible for the collection and reporting of data for each measure and for monitoring the overall process.

For each assigned performance measure, staff were directed to write an annual plan and a process to monitor the successful completion of the activities that was designed to impact the performance measure. Staff were also required to write an annual report for their assigned performance measure in which they commented on achievement of the objectives and

summarized progress on the work plan activities. Staff were provided trend data for their measure(s) from which they provided five-year target projections.

Following is a list of the new state-negotiated performance measures for the five-year cycle 2006-2010 along with planned activities for FY 2006.

#S1: The percent of healthy weight among women age 18-44. (Pyramid Level – PBS)

Application/Annual Plan FY 2006: 10/01/05-09/30/06

- Local MCH staff will participate in the development of local community walking programs. (Pyramid Level – PBS)
- State and local MCH staff will participate in promoting the 5+5 Program. (Pyramid Level – PBS)
- State and local MCH staff will be encouraged to participate in “low fat milk” campaigns within their community. (Pyramid Level – PBS)

#S2: The percent of women breastfeeding their infants at 6 months or longer. (Pyramid Level – PBS)

Application/Annual Plan FY 2006: 10/01/05-09/30/06

- Encourage local MCH staff to pursue the development of local breastfeeding coalitions. (Pyramid Level – IBS)
- Encourage local MCH staff to receive training and become certified as International Board Certified Lactation Consultants (IBCLC). State staff will assist in providing the training opportunity. (Pyramid Level – IBS)
- Encourage local MCH staff to participate in the biennial breastfeeding conference or other offered breastfeeding training. State staff will assist in the conference organization and planning. (Pyramid Level – IBS)
- Encourage participation in *HND* Breastfeeding Committee. (Pyramid Level – IBS)

#S3: The percent of women age 18-44 enrolled in Medicaid who receive a preventive dental service. (Pyramid Level – ES)

Application/Annual Plan FY 2006: 10/01/05-09/30/06

- State Oral Health Program Director will work with Medicaid to gather baseline data. (Pyramid Level – IBS)
- Promote the use of Project Will Show materials to local public health units, social services and case managers. (Pyramid Level – PBS)
- Encourage/assist local agencies to provide access to oral health screenings. (Pyramid Level – ES)
- Encourage/assist local agencies with resources to assure access to a source of health insurance coverage. (Pyramid Level – ES)

#S4: The degree to which women age 18-44 have access to preventive health services as measured by 5 indicators of health care access. (Pyramid Level – ES)

Application/Annual Plan FY 2006: 10/01/05-09/30/06

- Encourage/assist local agencies with resources to assure access to a source of health insurance coverage. (Pyramid Level – ES)
- Encourage/assist local agencies to encourage women to receive recommended preventive screening services such as blood cholesterol, bone mineral density, triglycerides and glucose, and body mass index. (Pyramid Level – ES)
- Encourage/assist local agencies to provide access to early and adequate prenatal care. (Pyramid Level – ES)
- Encourage/assist local agencies to provide access to mental health screenings, especially postpartum depression. (Pyramid Level – ES)
- Encourage/assist health professionals to screen and refer all women for family and intimate partner violence. (Pyramid Level – ES)

#S5: The rate of deaths to children age 1-19 caused by intentional and unintentional injuries per 100,000 children. (Pyramid Level – PBS)

Application/Annual Plan FY 2006: 10/01/05-09/30/06

- Re-apply for ND Department of Transportation funds to administer the state's child passenger safety program; monitor expenditures, complete reports as required. (Pyramid Level – IBS)
- Continue educational efforts to increase the proper use of car seats through use of pamphlets, posters, displays, etc. Sponsor Child Passenger Safety Week in February 2005. (Pyramid Level – PBS)
- Develop an educational campaign to inform ND parents and caregivers about changes in the state's child passenger safety law. Provide information on the appropriate restraint for their child's age, weight, height and developmental level. (Pyramid Level – PBS)
- Continue car seat distribution program throughout the state by providing car seats, policies/procedures and training/technical assistance to local agencies. Provide car seats and training to five Indian reservations. (Pyramid Level – IBS)
- Assist local agencies in conducting car seat check-ups by providing certified instructors, technicians, car seats and checkup supplies. (Pyramid Level – IBS)
- Continue coordinating the "Boost, Then Buckle" Campaign to encourage the use of booster seats by children from 40 to 80 pounds. Provide booster seats to local agencies to enhance the campaign. (Pyramid Level – PBS)
- Conduct 2-3 four-day NHTSA Standardized Child Passenger Safety Courses to certify new child passenger safety technicians. Conduct 2-3 refresher courses for current technicians and assist current technicians in meeting requirements for re-certification. (Pyramid Level – IBS)
- On an ongoing basis, provide technical assistance and updated information to technicians to maintain technical knowledge on child passenger safety issues. Write the "Buckle Update" section of the "Building Blocks to Safety" quarterly newsletter to provide current information on child passenger safety. (Pyramid Level – PBS)

#S6: The percent of children age 6-17 who exercised or participated in a physical activity that made him/her sweat and breathe hard, such as basketball, soccer, running, or similar aerobic activities on 5 or more days during the past week. (Pyramid Level – PBS)

Application/Annual Plan FY 2006: 10/01/05-09/30/06

- Encourage local MCH staff to partner in healthy school environment activities such as the USDA school wellness initiative. (Pyramid Level – PBS)
- Encourage local MCH staff to participate in *HND* Physical Activity Committee. (Pyramid Level – IBS)
- Local MCH staff will engage community child care associations, Head Start and WIC in promoting physical activity. (Pyramid Level – IBS)

#S7: The percent of ND children age 2-17 with a BMI in the normal weight range. (Pyramid Level – PBS)

Application/Annual Plan FY 2006: 10/01/05-09/30/06

- Encourage local MCH staff to partner in healthy school environment activities such as the USDA school wellness initiative within their communities. (Pyramid Level – PBS)
- Encourage local MCH staff participation in *HND* Physical Activity Committee. (Pyramid Level – IBS)
- State and local MCH staff will participate in promoting the 5+5 Program. (Pyramid Level – PBS)
- State and local MCH staff will be encouraged to participate in “low fat milk” campaigns within their community. (Pyramid Level – PBS)

#S8: The degree to which the state can assess and plan for the health and related service needs of children with extraordinary medical needs. (Pyramid Level – IBS)

Application/Annual Plan FY 2006: 10/01/05-09/30/06

- CSHS and stakeholders will establish criteria to objectively rank each of the components in the performance measure. (Pyramid Level – IBS)
- A working definition of children with extraordinary medical needs will be established and agreed upon by stakeholders. (Pyramid Level – IBS)
- CSHS will estimate the prevalence of medically fragile children in the state using Medicaid claims data. (Pyramid Level – IBS)
- CSHS staff will participate as requested in the interim legislative study of children with special health care needs in the state. (Pyramid Level – IBS)
- CSHS staff will participate in the Medical Needs Task Force co-facilitated by state CSHCN and Disability Services staff to assess the status of children with extraordinary medical needs in the state. (Pyramid Level – IBS)

#S9: The percent of families who reported they “had no problem at all” in getting care for their child from a specialist doctor. (Pyramid Level – IBS)

Application/Annual Plan FY 2006: 10/01/05-09/30/06

- CSHS will directly manage and fund a variety of multidisciplinary clinic services for CSHCNs and their families. (Pyramid Level – DHC)
- CSHS will report on the percentage of families that reported that the clinic they attended has helped them manage their child’s condition. (Pyramid Level – IBS)
- CSHS will review survey data to monitor specialty care access for CSHCN (e.g.) CSHCN survey, Child Health survey, etc. (Pyramid Level – IBS)
- CSHS will assess location and availability of pediatric specialists in the state. (Pyramid Level – IBS)

#S10: The percent of activities completed in the CSHS Public Information Services plan. (Pyramid Level – PBS)

Application/Annual Plan FY 2006: 10/01/05-09/30/06

- CSHS will develop a Public Information Services Plan that includes activities in the following areas: toll free number; targeted outreach, information and referral; resource library; education and consultation; marketing; and systems. (Pyramid Level – PBS)
- Quarterly meetings will be held to monitor the status of the public information services plan. (Pyramid Level – IBS)
- An annual report will be available to document plan accomplishments. (Pyramid Level – IBS)
- CSHS will coordinate with family organizations to determine effectiveness of information and referral efforts supported by CSHS. (Pyramid Level – IBS)

C. Needs Assessment Summary

Based on the Participant Survey that was completed prior to the Title V planning retreat, the top crosscutting health issues for the Maternal and Child Health Population included:

- Inadequate insurance coverage
- Lack of knowledge about resources and programs
- Access to dental care
- Lack of health insurance
- Poverty/Income
- Access to mental health services

Women, Mothers and Infants

ND has a declining birth rate. There are disparities for American Indians (infant mortality, death rate, poorer health outcomes, diabetes) but increases in “back to sleep” and breastfeeding. There are disparities in first trimester prenatal care and adequate prenatal care for low income and American Indian women and access issues for preventive services. Health risk factors include tobacco use during pregnancy, overweight and domestic violence incidents. There are system geographic access issues (provider shortages and location of various providers).

Based on the Participant Survey that was completed prior to the Title V planning retreat, the top health issues for Women, Mothers and Infants included:

- Prenatal care
- Prenatal tobacco use
- Alcohol use
- Breastfeeding
- Domestic violence/abuse

These overall results are relatively consistent with the quantitative analysis provided for the above population group.

Children and Adolescents

The overall child population is declining while increases are noted in two-parent working families and disparities for American Indian children in poverty. The overall child death rate is lower than the national rate with disparities for American Indian children. ND has a declining uninsured population and an increasing immunization percentage. The state is experiencing a declining teen pregnancy and teen birth rate but problems with tobacco, alcohol, overweight, and Chlamydia. There are issues in access to school nurses, child care and pediatricians.

Based on the Participant Survey that was completed prior to the Title V planning retreat, the top health issues for Children and Adolescents included:

- Adolescent drug and alcohol use
- Healthy weight
- Access to health care
- Adolescent tobacco use
- Youth violence/bullying

These overall results are relatively consistent with the quantitative analysis provided for the above population group.

Children with Special Health Care Needs

Nearly twelve and one-half percent (12.4) of children have a special health care need with American Indian children at a higher percentage than White children. Health status indicators include diabetes, asthma, and hospitalization for mental and behavioral disorders. Increases were noted in use of some related programs and services, but families still struggle with access. Increases were noted in screening (hearing, metabolic, EPSDT). Families with CSHCN continue to have financial issues and experience access problems despite a higher than national percentage who indicated services are organized for easy use.

Based on the Participant Survey that was completed prior to the Title V planning retreat, the top health issues for Children with Special Health Care Needs included:

- Availability of specialists
- Impact on families
- Lack of support/ancillary services
- Transition to adulthood
- Lack of screening programs and early intervention services
- Family participation/involvement

These overall results are relatively consistent with the quantitative analysis provided for the above population group.

The following priority needs were identified through the current five-year needs assessment process:

- To increase physical activity and healthy weight among women.
- To increase the initiation and duration of breastfeeding.
- To increase access to dental services for low-income women.
- To increase access to preventive health services for women.
- To reduce the rate of intentional and unintentional injuries among children and adolescents.
- To increase physical activity among pre-school and school-age children.
- To increase the percent of healthy weight among children and adolescents.
- To reduce the impact of chronic health conditions on children.
- To improve geographic access to pediatric specialty care providers.
- To increase information and awareness about available services.

The following needs had been identified in the previous five-year needs assessment:

- For children to receive necessary health care services in school
- To increase the percentage of Medicaid eligible children who receive dental services
- To reduce the rate of abuse and neglect in infants and children
- To increase the percent of young adults who are of normal weight
- To increase the number of pregnancies that are intended
- The effects of prenatal and maternal smoking on infant health
- For women of childbearing age to use folic acid
- To reduce the number of deaths due to unintentional injuries to children and adolescents
- To reduce the impact of congenital anomalies and chronic health conditions on children and their families
- For children with special health care needs to receive necessary specialty care and related services

Several changes were apparent since the last block grant application. Although not exact, a similar process was used to determine needs for the FY 2006 application, as that used in the prior five-year needs assessment. A workgroup was used to organize and plan for the assessment and a stakeholder planning retreat was held after the data was collected and analyzed to prioritize needs for the MCH population. In both instances, after the planning retreats were held, Title V staff developed work plans to address performance measures based on current capacity.

D. Health Status Indicators

Health Status and Health Systems Capacity Indicators were examined as part of the five-year needs assessment process. Refer to State Overview, F. Health Systems Capacity Indicators for trends and a description of any difficulty in data collection and/or analysis.

E. Outcome Measures – Federal and State

Federal Outcome Measures:

The percent of newborns who are screened and confirmed with condition(s) mandated by their State-sponsored newborn screening programs (e.g. phenylketonuria and hemoglobinopathies) who receive appropriate follow-up as defined by their state.

Major work efforts focus around implementation of expanded screening, coordinated management and collaboration. The target of 100 percent was achieved. Activities are not expected to change significantly in the future, as current activities have been successful. However, expanded screening has lead to increased staff/resource demands for both short and long term follow-up.

The percent of children with special health care needs age 0-18 years whose family partner in decision making at all levels and are satisfied with the services they receive.

Major work efforts focus around a CSHS Family Advisory Council, quality assurance assessments and support of family organizations that provide health information training and emotional support. Based on CSHCN SLAITS data, the target of 61.5 percent was met. Families served through CSHS annually report high levels of satisfaction; hence, percentages for this measure are expected to increase over time.

The percent of children with special health care needs age 0-18 who receive coordinated, ongoing, comprehensive care within a medical home.

Major work efforts focus around increasing awareness, collaboration with others to initiate medical home implementation, and enhanced care coordination. Based on CSHCN SLAITS data, the target of 54.7 percent was met. Technical assistance may be needed to assure progress beyond informational/promotional activities to implementation.

The percent of children with special health care needs age 0-18 whose families have adequate private and/or public insurance to pay for the services they need.

Major work efforts focus around provision of diagnostic and treatment services, outreach activities, and participation in Medicaid policy decision-making. Based on CSHCN SLAITS data, the target of 62 percent was met. Many families served through CSHS have private health insurance, however, underinsurance continues to be an issue.

Percent of children with special health care needs age 0-18 whose families report the community-based service systems are organized so they can use them easily.

Major work efforts focus around training and technical assistance for local staff, participation on interagency workgroups, operation of a family resource center, and

provision of multidisciplinary clinics. Based on CSHCN's SLAITS data, the target of 83.4 percent was met.

The percent of youth with special health care needs who received the services necessary to make transition to all aspects of adult life.

Major work efforts focus around collaboration through a Transition Steering Council, information and referral for the SSI population, and the promotion of transition through information and service plan activities. Based on CSHCN's SLAITS data, the target of 5.8 percent was met. Technical assistance may be needed to assure progress on this measure.

Percent of 19 to 35 month olds who have received full schedule of age appropriate immunizations against Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza and Hepatitis B.

Major work efforts focus around collaboration with the State Immunization Program, funding to local public health units to administer immunization programs, and providing educational trainings and updates. The actual indicator for this performance measure (78.4%) was slightly under the target of 79.5 percent. Currently, the state has universal coverage for children; however, reductions in federal funds may put this in jeopardy.

The birth rate (per 1,000) for teenagers aged 15 through 17 years.

Major work efforts focus around collaboration with Family Planning, Adolescent Health and the STD/HIV Programs. In addition, abstinence funding continues to be distributed to all regions within the state. The actual indicator for this performance measure (10.2) was slightly under the target rate of 11.5. Between 1992 and 2000, ND had a 29 percent decline in the teen pregnancy rate. ND also has the lowest rate (71) of pregnancy per 1000 women age 15-19 in the nation.

Percent of third grade children who have received protective sealants on at least one permanent molar tooth.

Major work efforts focus around strengthening the oral health coalition, development of a state oral health plan, and data analysis of a third grade oral health basic screening survey. The actual indicator for this performance measure (53.6%) was slightly under the target of 55 percent but above the Healthy People 2010 goal of 50 percent.

The rate of deaths to children aged 14 years and younger caused by motor vehicle crashes per 100,000 children.

Major work efforts focus around a car seat distribution program, development of an educational campaign about changes in the state's child passenger safety law, and ongoing technical assistance and education. The actual indicator for this performance measure (5.6) was higher than the target of 2.8.

Percentage of mothers whom breastfeed their infants at hospital discharge.

Major work efforts focus around collaboration with WIC to implement a peer-counseling program, promotion of third-party reimbursement for lactation consultant services, and technical assistance and education. The actual indicator for this performance measure

(61.3%) was lower than the target of 63 percent. Attempts to mandate designated breastfeeding areas within the workplace have failed during the past two legislative sessions.

Percentage of newborns who have been screened for hearing impairment before hospital discharge.

Major work efforts focus around the annual administration of a newborn screening survey, participation on the Early Hearing Detection and Intervention (EHDI) grant management team, and activities as Title V state EHDI contact. The actual indicator for this performance measure (95.1) was higher than the target of 95 percent. New grant funding will support enhanced follow-up and integration activities.

Percent of children without health insurance.

Major work efforts focus around participation in the Robert Wood Johnson Covering Kids and Families Initiative, monitoring enrollment levels in health insurance programs, and providing technical assistance and education to local public health departments. The actual indicator for this performance measure (7.5%) was slightly below the target of 7.7 percent. From January 2003 to March 2005, the number of children enrolled in coverage programs increased by 1,747, a 6 percent statewide increase.

Percent of potentially Medicaid-eligible children who have received a service paid by the Medicaid Program.

Major work efforts focus around regular meetings with Medicaid and Health Tracks staff and analysis of claims data. The actual indicator for this performance measure (75.7%) was lower than the target of 80 percent. Future Medicaid funding may influence progress on this measure.

The percent of very low birth weight infants among all live births.

Major work efforts focus around provision of funding to local public health units to support the Optimal Pregnancy Outcome Program, participation in the Fetal Alcohol Syndrome Task Force, and collaboration with WIC to provide nutritional education. The actual indicator for this measure (1.2%) was slightly higher than the target of 1.0 percent.

The rate (per 100,000) of suicide deaths among youths aged 15 through 19.

Major work efforts focus around coordinating the State Adolescent Suicide Prevention Task Force, assisting the Mental Health Association in identifying funding to continue suicide prevention efforts, and updating the state plan for adolescent suicide prevention. The actual rate for this measure (9.9) is lower than the target of 10.5. While adolescent suicide rates show decreasing trends, the adult suicide rate is increasing. Future plans are to include the adult population in prevention activities.

Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates.

The state has chosen not to monitor this performance measure. The actual indicator for this measure (45%) was below the target of 60 percent. Past analysis in 2002 indicated a majority of the very low birth weight (VLBW) babies were born at the Level III hospitals and they tended to have more health problems/complications than did the babies born at other hospitals. When controlling for these confounding factors:

- VLBW babies born at one of these Level III hospitals or at a second group of other large hospitals had more than double the chance of survival than did very low birth weight babies born at any of the other hospitals in ND.
- There was no statistical difference in their survival rates for babies born at the level 3 hospitals and those born at other large hospitals.

Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.

Major work efforts focus around providing funding to local public health units to support the Optimal Pregnancy Outcome Program, funding to two Tribal entities to support prenatal care programs, and collaboration with NDSU for submission of pending PRAMS grant application. The actual indicator for this measure (84.9%) was slightly below the target of 85.5 percent.

State Outcome Measures:

Future work efforts impacting the new state performance measures are addressed in B. 5. Selection of State Priority Needs, as are baseline targets.